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QUALITÉ DE VIE DES ENFANTS ATTEINTS DE CANCER EN SOINS PALLIATIFS : PERSPECTIVE DES SOIGNANTS

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Sommaire

Les soins palliatifs pédiatriques (SPP) constituent un service nécessaire ayant pour visée principale de maintenir et d'améliorer la qualité de vie (QdV) des enfants atteints d'une maladie potentiellement mortelle (World Health Organization, 2017). Dans le domaine de l'oncologie pédiatrique, bien qu'il existe un grand nombre d'écrits scientifiques au sujet de la QdV des patients en cours de traitement curatif et survivants, très peu de données empiriques sont disponibles concernant la QdV des enfants atteints d'un cancer avancé et recevant des SPP. Il est ainsi difficile pour les cliniciens de définir et mesurer la QdV auprès de cette population. Considérant que les informations issues de l'évaluation de la QdV permettent d'ajuster les soins et le support donnés aux enfants et aux familles, il s'avère nécessaire d'éclaircir la notion de QdV en SPP et de connaître les critères et les moyens qui devraient être utilisés pour évaluer le niveau de QdV des enfants dans ce contexte spécifique. En ce sens, le premier objectif de la présente étude est de décrire le concept de QdV, dans le contexte des SPP en oncologie, selon la représentation des soignants dans ce domaine. Le second a pour but de décrire les signes indicatifs et les approches utilisées par les soignants pour évaluer la QdV des enfants qu'ils accompagnent et recenser leurs recommandations pour améliorer cette évaluation. Pour ce faire, des entrevues semi-dirigées ont été réalisées auprès de 20 professionnels de la santé du service d'Hémato-Oncologie du CHU Sainte-Justine ayant accompagné au moins un enfant atteint de cancer avancé en SPP. Un devis de recherche qualitatif a été privilégié et le contenu des entrevues a été analysé selon l'analyse thématique (Paillé & Mucchielli, 2012). Les résultats associés au premier objectif de la recherche ont permis d'identifier

sept dimensions de la QdV: Être suffisamment confortable sur le plan physique; Être apaisé dans sa souffrance psychologique; Être dans la vie, vivre des moments de plaisir au quotidien; Avoir un sentiment de contrôle sur sa vie; Avoir le sentiment que la vie continue; Avoir le sentiment d'être estimé et reconnu; Être en relation avec des personnes significatives. Quant aux résultats liés au deuxième objectif, ils mettent en évidence l'absence de critères préétablis pour évaluer la QdV. Les recommandations des soignants pour optimiser cette évaluation soulignent quant à elles l'importance du travail de collaboration entre les membres de l'équipe interdisciplinaire ainsi que la nécessité de collaboration avec l'enfant et sa famille. La description de ces dimensions de la QdV aide à préciser les critères de soins pour maintenir et améliorer la QdV des enfants atteints de cancer et recevants des SPP, alors que les résultats liés au deuxième objectif soutiennent la démarche de développement d'une méthode de mesure systématique de la QdV dans ce contexte.

Mots-clés : Qualité de vie, soins palliatifs pédiatriques, cancer, soignants, évaluation, enfants

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Introduction

Le cancer est la cause dominante de mort non accidentelle chez les enfants (Société canadienne du cancer, 2017). Le taux de mortalité annuel qui y est associé est estimé à 20% (Comité consultatif de la société canadienne du cancer, 2017). Lorsque la maladie menace la vie d'un enfant ou d'un adolescent et que les options thérapeutiques s'amenuisent, l'objectif de la prise en charge médicale n'est plus seulement de guérir ou de prolonger la vie, mais aussi d'octroyer des soins de support visant à prévenir et soulager la souffrance de l'enfant et à soutenir les besoins de la famille (Association canadienne de soins palliatifs, 2006 ; Gouvernement du Québec, 2006).

Les enfants atteints de cancer avancé éprouvent une souffrance substantielle ; la majorité souffre de symptômes physiques, comme la douleur, ou de détresse émotionnelle comme l'anxiété (Pritchard et al., 2008 ; Theunissen et al., 2007 ; Wolfe et al., 2000). Des effets secondaires intolérables et des risques de complications liés aux soins peuvent s'ajouter au portrait clinique. Des décisions complexes en ce qui concerne les alternatives thérapeutiques doivent également être prises par la famille et l'équipe soignante. Un tel contexte est propice à des divergences d'opinions qui sont parfois sources de conflits entre la famille et l'équipe de soins ainsi qu'entre les divers professionnels (Gauvin & Larose, 2012). L'intégration des soins palliatifs pédiatriques (SPP) constitue alors un service essentiel qui a pour objectif de maintenir et d'améliorer la qualité de vie (QdV) de l'enfant et de sa famille (Liben, Papadatou, & Wolfe, 2008).

Toutefois, à ce jour, bien que la QdV soit au cœur de la philosophie des SSP (Association canadienne de soins palliatifs, 2006), il existe encore très peu de données empiriques permettant de décrire ses dimensions et les stratégies utilisées par les soignants pour l'évaluer dans ce contexte spécifique. Il s'avère ainsi difficile pour les cliniciens d'appuyer leurs pratiques sur des données probantes afin d'assurer que leurs interventions aient un effet bénéfique sur la QdV des enfants atteints d'un cancer avancé nécessitant des SPP.

Les soins palliatifs pédiatriques

Les SPP sont des soins actifs et complets englobant les dimensions physique, psychologique, sociale et spirituelle. Leur visée principale est de maintenir et d'améliorer la QdV des patients atteints d'une maladie potentiellement mortelle (Association canadienne de soins palliatifs, 2006 ; Gouvernement du Québec, 2006). Ainsi, ils s'adressent à une population d'enfants présentant des caractéristiques et besoins distincts selon leur condition médicale. Cette population se divise en six catégories selon les caractéristiques qui leur sont propres (Gouvernement du Québec, 2006). Le tableau 1 présente chacun de ces groupes. En ce qui concerne les enfants atteints de cancer, ils sont inclus dans le premier groupe et représentent de 20 à 30 % de la population d'enfants recevant des SPP (Feudtner et al., 2011 ; Groupe de travail de soins palliatifs pédiatriques de l'Association Européenne de Soins Palliatifs Onlus, 2009 ; Widger et al., 2007).

Tableau 1

Population bénéficiant de soins palliatifs en contexte pédiatrique[1]

Groupes	Description
Groupe 1	Enfants présentant des conditions pour lesquelles un traitement curatif est possible. Les soins palliatifs peuvent être nécessaires pendant des périodes d'incertitude ou quand les traitements curatifs sont inefficaces.
Groupe 2	Enfants présentant des conditions où une mort prématurée est inévitable. Ces enfants peuvent avoir besoin de longues périodes de traitements intensifs destinés à prolonger leur vie et à leur permettre de participer à des activités normales pour des enfants de leur âge.
Groupe 3	Enfants présentant des conditions progressives sans espoir de guérison. Les traitements offerts à ces enfants sont uniquement palliatifs et peuvent s'étendre sur des années.
Groupe 4	Enfants présentant des problèmes neurologiques graves accentuant leur vulnérabilité et accroissant les risques de complications pouvant amener une détérioration non prévisible, mais considérée comme non progressive, de leur état.
Groupe 5	Nouveau-nés dont l'espérance de vie est très limitée.
Groupe 6	Membre d'une famille ayant perdu un enfant de façon imprévue à la suite d'une maladie, d'une situation engendrée par une cause externe ou d'une perte dans la périnatalité.

Concrètement, les SPP s'inscrivent dans une approche globale de la personne et incluent des services de soutien pour la famille. L'environnement social de l'enfant, son

[1] Tiré de Gouvernement du Québec. (2006). *Normes en matière de soins palliatifs pédiatriques: Groupe de travail sur les normes en matière de soins palliatifs pédiatriques*.

niveau de développement sur les plans physique, cognitif, affectif et spirituel ainsi que le rôle et les besoins des membres de la famille, incluant la fratrie et les grands-parents, doivent ainsi être pris en considération lors de la prestation des soins. L'organisation de ce type de soins nécessite une équipe multidisciplinaire dont l'approche est transversale et souple afin de s'adapter aux ressources et aux besoins de l'enfant et sa famille (Association canadienne de soins palliatifs, 2006; Cyr, 2012; Gouvernement du Québec, 2006).

Une distinction est également à faire entre les SPP, les soins curatifs et les soins de fin de vie. Pendant que la médecine curative se concentre sur l'identification et le traitement de la maladie et que les soins de fin de vie sont centrés sur la période précédant le décès, les SPP sont principalement axés sur la réduction des souffrances pendant le cours de la maladie et le suivi de deuil après le décès (Lassaunière, 2009). La figure 1 présente le parcours relatif des SPP durant la trajectoire de la maladie et après le décès (Association canadienne de soins palliatifs, 2006). La barre oblique hachurée marque la distinction entre les soins curatifs et les SPP. Il s'agit d'un partage relatif des soins qui varient selon chaque enfant en fonction de la situation qui leur est propre. La barre hachurée verticale indique quant à elle le fait que les SPP se poursuivent après le décès. La prise en charge par l'équipe de SPP devrait donc entrer en vigueur dès l'annonce du diagnostic de la maladie menaçant la vie et se poursuivre durant la période de deuil (World Health Organization, 2017). Les SPP ne sont ainsi pas spécifiques à la fin de vie, mais plutôt

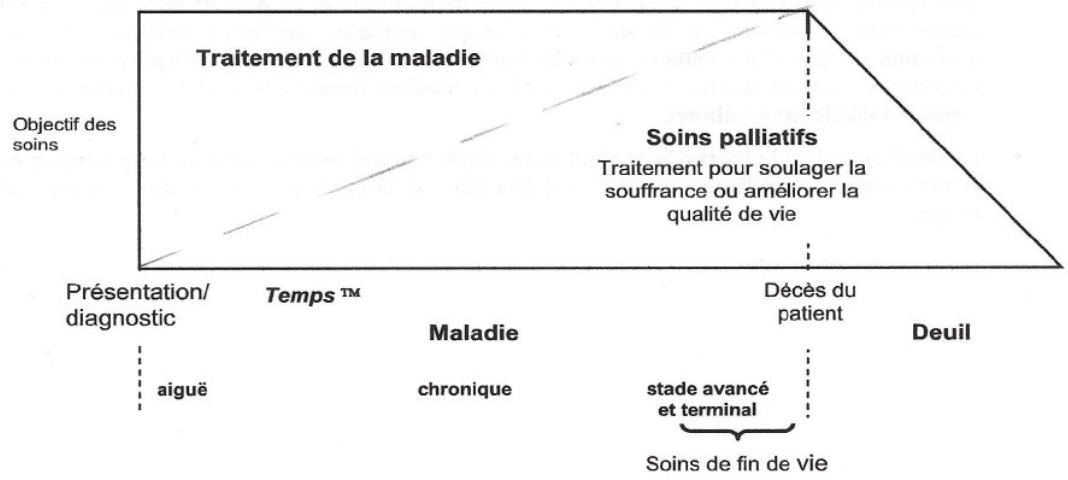

Figure 1. Le rôle des soins palliatifs pédiatriques (Association canadienne de soins palliatifs, 2006)

orientés vers la vie avec pour mission de faire en sorte qu'elle soit de la meilleure qualité possible (Humbert, 2012).

La qualité de vie

La QdV est un concept complexe qui mène à une large diversité quant à sa définition et ses critères de mesure. Depuis l'émergence de ce concept, dans les années soixante, plusieurs chercheurs provenant de domaines variés, comme la psychologie, les sciences biomédicales et les sciences sociales, ont mené des études afin de la conceptualiser et l'opérationnaliser (Moons, Budts, & Geest, 2006). À ce jour, la définition de la QdV la plus couramment utilisée par les cliniciens et chercheurs est celle établie par l'Organisation mondiale de la santé (OMS) en 1994 (Anquier, Simeoni, & Robitail, 2006; Gladis, Gosh, Dishuk, & Crits-Christoph, 1999):

> La perception qu'a l'individu de sa place dans l'existence, dans le contexte de la culture et du système de valeurs dans lequel il vit, en relation avec ses objectifs, ses attentes, ses normes et ses inquiétudes. Il s'agit d'un large champ conceptuel, englobant de manière complexe la santé physique de la personne, son état psychologique, son niveau d'indépendance, ses relations sociales, ses croyances personnelles et sa relation avec les spécificités de son environnement.

La QdV est aussi reconnue comme étant un concept complexe à caractère multidimensionnel et subjectif. Elle relève donc de la cooccurrence de plusieurs dimensions et réfère principalement à l'appréciation par le sujet de sa QdV (Candel & Dubois, 2005).

Néanmoins, bien que la définition de la QdV établie par l'OMS soit la plus couramment utilisée par les cliniciens et chercheurs, il existe une multitude de définitions de la QdV qui varient selon les écoles de pensée, la diversité des lieux de vie, des cultures et des conditions de développement de la société (Fernandez-Petite, 2007).

La qualité de vie et les soins palliatifs pédiatriques en oncologie

Dans le domaine de la santé, c'est le besoin d'aider les soignants à se faire une image plus complète du statut de santé de l'enfant, d'évaluer les bénéfices des soins de santé offerts par des professionnels ainsi que celui d'orienter les options de traitements qui sont à la source du développement des premières études au sujet de la QdV (Moons et al., 2006).

Du côté de l'oncologie pédiatrique, des avancées considérables ont ainsi été réalisées au cours des dernières décennies, pour clarifier le concept de QdV et développer des instruments de mesure pour l'évaluer.

D'une part, divers auteurs ont mené des études pour décrire plus précisément les dimensions de la QdV des enfants atteints de cancer. De façon relativement comparable à la définition de la QdV établie par l'OMS (1994), la santé physique, l'état psychologique et les relations sociales ont été identifiés comme étant les principales dimensions de la QdV (Anthony et al., 2014 ; Pépin, Carret, & Sultan, 2015). Quelques données empiriques ont quant à elles distinctivement mis de l'avant que la QdV en oncologie pédiatrique dépend généralement des symptômes de l'enfant, de son niveau de participation aux activités habituelles et de sa perception associée au fait d'être malade (p. ex., Hinds et al., 2004 ; Hinds, Burghen, Haase, & Phillips, 2006; Leplège, 1999).

D'autre part, divers instruments de mesure ont été développés et validés pour évaluer la QdV des enfants atteints de cancer. Le tableau 2 décrit les quatre instruments de la QdV en oncologie pédiatrique qui, à notre connaissance, sont actuellement les plus utilisés. Pour l'ensemble de ces instruments de mesure, les principales dimensions évaluées sont les dimensions physique, psychologique et sociale. La majorité utilise des échelles de type Likert et est orientée vers la présence ou l'absence de symptômes, de plaintes ou sur le niveau de pertes de capacité fonctionnel de l'enfant (Davis et al., 2006; Gladis et al., 1999). Le principal répondant est l'enfant (version auto-rapportée) ou ses parents (version

Tableau 2

Instruments de mesure les plus utilisés de la qualité de vie en oncologie pédiatrique

Instrument de mesure	Auteur (s)	Type de mesure	Répondants	Période de rappel	Dimensions	Types de réponses
Memorial Symptom Assessment Scale (MSAS) MSAS 10-18	Collins et al. (2000)	Spécifique[2] (cancer)	Version auto-rapportée	1 semaine	Expérience des symptômes physiques, psychologiques et détresse globale	Échelle Likert (0 à 4) pour les symptômes de détresse Échelle Likert (1 à 4) pour la fréquence des symptômes
Pediatric Oncology Quality of life Scale (POQOLS)	Goodwin, Boggs et Grham-Pole (1994)	Spécifique (cancer)	Version parent	2 semaines	Fonctionnement physique et restriction de rôle, détresse émotionnelle et réaction au traitement en cours	Échelle Likert en 7 points (Jamais à très souvent)

[2] L'outil spécifique s'adresse à une population d'individu atteint d'une maladie spécifique (Missotten, Étienne, & Dupuis, 2007)

Instruments de mesure les plus utilisés de la qualité de vie en oncologie pédiatrique (suite)

Instrument de mesure	Auteur (s)	Type de mesure	Répondants	Période de rappel	Dimensions	Types de réponses
Pediatric Quality of Life (PedsQL 4.0)	Varni, Seid et Kurtin (2001)	Modulaire[3]	Version auto-rapportée Version parent	1 mois	Fonctionnement physique, émotionnel, social et scolaire.	Échelle Likert (0 à 4)
The Pediatric Cancer Quality of Life Inventory-32 (PCQL-32)	Varni, Katz, Seid, Quiggins et Friedman-Bender (1998)	Spécifique (cancer)	Version auto-rapportée Version parent	1 mois	Symptômes liés au traitement et fonctionnement physique, psychologique, social ou interpersonnel et cognitif	Échelle Likert (0 à 3)

[3] L'outil modulaire est la combinaison d'éléments génériques (s'adressant à tout individu) et spécifiques à la maladie (Missotten, Étienne, & Dupuis, 2007)

parent) et la période de rappel, période à laquelle le répondant doit se référer pour déterminer la QdV du jeune, varie d'une semaine à un mois.

En regard de ces avancées, il est maintenant reconnu que les informations issues de l'évaluation de la QdV contribuent aux prises de décisions thérapeutiques et sont utiles dans l'amélioration de la prise en charge globale de l'enfant atteint de cancer (Gouvernement du Québec, 2006).

Or, de récentes données probantes mettent en évidence une nuance considérable concernant les dimensions et instruments de mesure actuels de la QdV en oncologie pédiatrique : ils reposent sur des études circonscrites à la population d'enfants survivants du cancer ou en cours de traitements curatifs. Ces dimensions et instruments de mesure ne peuvent donc pas rendre compte de la réalité spécifique de la population d'enfants atteints de cancer avancé recevant des SPP (Coombes, Wiseman, Lucas, Sangha, & Murtagh, 2016 ; Hinds et al., 2006; Huang et al., 2010). D'ailleurs, à cet effet, les résultats d'une récente recension systématique des écrits, réalisée dans le but de vérifier si les mesures existantes de la QdV en pédiatrie peuvent s'appliquer à la population d'enfant en SPP, indiquent qu'aucune des mesures actuelles en oncologie ne tient compte des spécificités propres aux SPP. Par exemple, plusieurs items du PedsQL 4.0, outil le plus utilisé pour évaluer la QdV en oncologie pédiatrique, ne considèrent pas les capacités physiques limitées de ces jeunes (Huang et al., 2010). De plus, la majorité des mesures n'intègrent pas toujours une temporalité adaptée aux SPP où il est plutôt recommandé de

se concentrer sur de petites périodes de temps afin d'accroître la sensibilité de l'évaluateur vis-à-vis la variabilité de la QdV dans le temps (Coombes et al., 2016). Les mesures ne capturent pas non plus à elles seules les préoccupations courantes reliées à ce contexte tel que le maintien de l'espoir et la communication avec l'équipe de soins (Cataudella et al., 2014).

En fait, à ce jour, seulement quelques auteurs se sont spécifiquement penchés sur la question de la QdV dans le contexte précis des SPP en oncologie (p. ex., Barrera, D'Agostino, Gamon, Spencer, & Baruchel, 2005; Friedrichsdorf et al., 2015 ; Knapp et al., 2012 ; Tomlinson, Hinds, Bartels, Jendershot, & Sung, 2011). De façon générale, comme pour la population d'enfants survivants ou en cours de traitement pour le cancer, les résultats révèlent que le bien-être physique de l'enfant occupe une place centrale dans sa QdV. Une grande importance est également accordée à l'impact des pertes et des symptômes occasionnés par la maladie (p. ex., la fatigue) sur le fonctionnement de l'enfant au quotidien (p. ex, Knapp et al., 2012 ; Tomlinson et al., 2011). Certains ont, quant à eux, ouvert la voie à la considération de composantes positives de la QdV dans ce contexte, tels que le maintien du sentiment de normalité de l'enfant et du plaisir au quotidien (p. ex., Barrera et al., 2005; Friedrichsdorf et al., 2015; Hechler et al, 2006 ; von Lützau et al., 2012). Toutefois, il n'en demeure pas moins que ces conclusions reposent sur un bassin d'études restreint et que l'absence de consensus en regard des dimensions de la QdV associées au contexte de SPP laisse planer une ambiguïté invitant à poursuivre l'exploration en vue de clarifier le concept.

De plus, ces dernières études ont essentiellement été réalisées auprès d'enfants atteints de cancer avancé et de leurs parents (p. ex., Barrera et al., 2005; Friedrichsdorf et al., 2015; Hechler et al, 2006; Tomilinson et al., 2011; von Lützau et al., 2012). Le point de vue des soignants a, quant à lui, fait l'objet de très peu d'études et les mesures actuelles en oncologie pédiatrique ne tiennent généralement pas compte de leur perspective et expérience. À vrai dire, les auteurs ayant évalué la représentation des soignants en SPP se sont davantage centrés sur la description des critères de la qualité des soins que sur l'exploration de la notion de QdV dans ce contexte (Andersen, Seecharan, & Toce, 2004). Pourtant, par la diversité de leur rôle ainsi que par leur expérience acquise auprès des multiples familles qu'ils ont accompagnées, leur perspective quant à la QdV de l'enfant permettrait certainement d'apporter un regard complémentaire à ceux de l'enfant et de ses parents. Explorer leur représentation de la QdV des enfants qu'ils accompagnent est également l'occasion de les amener à s'interroger sur leur propre pratique en vue de fixer des objectifs de soins plus clairs et plus spécifiques au contexte de SPP (Mulhern et al., 1989; Pellegrino, 2000).

En somme, considérant que, d'une part une définition claire de l'objet à mesurer est essentielle pour obtenir des mesures de qualités permettant aux soignants d'améliorer leurs interventions (Candel & Dubois, 2005), il semble d'abord nécessaire que le concept de QdV dans le domaine des SPP en oncologie soit davantage exploré et que ses dimensions soient précisées. En ayant une description plus claire de la QdV en SPP, il sera certainement plus aisé pour les soignants d'établir des critères explicites de la QdV

dans ce domaine. D'autre part, considérant que les outils actuels en oncologie ne permettent pas d'évaluer la QdV spécifiquement chez les enfants atteints d'un cancer en SPP et que les critères précis sur lesquels se basent les soignants pour juger de la QdV sont à ce jour inconnus, il paraît indiqué d'explorer leurs pratiques d'évaluation de la QdV (Cataudella et al., 2014; Huang et al., 2010; Krakowski, Chardot, Bey, Guillemin, Philip, 2001 ; Morley et al., 2014; Ravens-Sieberer & Bullinger, 1998).

Objectifs

La présente thèse a pour objectif général de dresser un portrait de la QdV selon l'expérience et le point de vue de soignants ayant accompagné des enfants atteints de cancer avancé en SPP. Il est attendu que l'identification des dimensions de la QdV et l'exploration de la pratique actuelle des soignants quant à son évaluation apportent des informations concrètes concernant la QdV dans le contexte des SPP en oncologie. Il est ainsi souhaité que ces informations soient favorables à la communication entre les soignants et puissent servir de base à l'élaboration d'une procédure spécifique d'évaluation de la QdV. La procédure a été approuvée par le comité d'éthique Lettres et sciences humaines de l'Université de Sherbrooke ainsi que par le comité d'éthique du CHU Sainte-Justine (voir les certificats d'éthique à l'Appendice A et B ainsi que le formulaire d'information et de consentement à l'Appendice C).

Le premier objectif spécifique consiste à identifier les dimensions permettant de décrire la QdV de l'enfant atteint d'un cancer et suivi en SPP à partir de la représentation des

professionnels en hématologie-oncologie pédiatrique. Pour ce faire, 20 soignants de professions variées ont été rencontrés. Leur discours a fait l'objet d'une analyse thématique visant à décrire la QdV. Les résultats associés à cet objectif sont présentés dans le premier chapitre de cette thèse sous la forme d'un article intitulé « *Identifying Domains of Quality of Life of Children with Cancer in Palliative Care: A Qualitative Study with Professionals.* » et publié dans la revue *Palliative and Supportive Care* (Avoine-Blondin, Parent, Lahaye, Humbert, Duval & Sultan, 2017).

Le deuxième objectif vise à identifier les signes et les modes d'approches qu'ils utilisent pour évaluer la QdV et à recenser leurs recommandations pour optimiser cette évaluation en contexte de SPP. Une nouvelle analyse thématique du discours des participants a alors été réalisée en regard à cet objectif. Les résultats issus de cette analyse sont présentés dans le deuxième chapitre de cette thèse sous la forme d'un article soumis et en cours de révision à la revue *BMC Palliative Care* et intitulé « *How do professionals assess the Quality of Life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement?*» (Avoine-Blondin, Parent, Fasse, Lopez, Humbert, Duval & Sultan, soumis ; voir Appendice D).

Chapitre I

Identifying domains of quality of life in children with cancer undergoing palliative care: A qualitative study with professionals

Identifying domains of quality of life in children with cancer undergoing palliative care: A qualitative study with professionals

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ABSTRACT

Objective: The goal of pediatric palliative care (PPC) is to maintain the quality of life (QoL) of children whose lives are threatened. However, there are sparse scientific data on the domains of QoL in this particular context, and no measurement strategies are available. The present study aims to describe the domains of QoL in the context of PPC in oncology, according to the perceptions of professional caregivers.

Method: Semistructured interviews were conducted with a random sample of 20 professional caregivers from the Division of Hematology/Oncology at Le Centre Hospitalier Universitaire Sainte-Justine (Montréal, Canada). The caregivers were asked about their perceptions about the QoL of the children they have cared for in this context. The data were analyzed using inductive thematic content analysis.

Results: The analysis allowed us to identify seven domains of QoL: "physical comfort," "alleviation of psychological suffering," "fun and the present moment," "sense of control," "feeling valued and appreciated," "feeling that life goes on," and "meaningful social relationships."

Significance of Results: Caregivers recount the regard that should be accorded to maintaining well-being and a sense of fun, as well as fostering the child's abilities, taking account of the progression of the disease, and to fulfilling his or her needs, especially social ones. Our results also demonstrate that all domains were positively referred to by professional caregivers. The data from our study will lead to better assessment of QoL according to the trajectory of a child with advanced cancer while undergoing PPC.

Key words: Pediatric palliative care, Quality of life, Cancer, Professionals, Qualitative study

INTRODUCTION

Recent advances have contributed to improving the curative care of children with cancer and increasing their survival rate. However, no less than 20% of young individuals with cancer die each year (Comité consultatif de la Société Canadienne du Cancer, 2015). Pediatric palliative care (PPC) is about helping children and their families deal with this medical condition while optimizing their quality of life (QoL) (Association Canadienne de Soins Palliatifs, 2006; Gouvernement du Québec, 2006; World Health Organization, 2013).

In order to describe and evaluate QoL in the specific context of PPC in oncology, various authors have collected the points of view of children with advanced cancer or those of their parents (Barrera et al., 2005; Friedrichsdorf et al., 2015; Hechler et al, 2006; Tomlinson et al., 2011; von Lützau et al., 2012). These studies depict a portrait of QoL that highlights the traditional dimensions of physical, emotional, and social QoL (Pépin et al., 2015). Functional deficits in terms of mobility, sensation, and self-care, as well as pain and fatigue levels, were the main indicators used to evaluate the QoL of these young individuals (Tomlinson et al., 2011). Research has also highlighted the more positive components of QoL—such as maintaining the child's sense of normalcy, focusing on family activities, maintaining hope, and having fun or taking pleasure (Barrera et al., 2005; Friedrichsdorf et al., 2015; Hechler et al, 2006; Kamper et al., 2010; von Lützau et al., 2012).

In contrast with these reports, the instruments that are now available to evaluate QoL in the pediatric context—and are thus likely to be applied in PPC—remain focused on

symptoms or functional deficits and are based on inappropriate time perspectives (e.g., months) (Hinds et al., 2006; Liben et al., 2008). Importantly, no specific QoL instruments have been developed for the PPC context, as was evidenced in a recent systematic review conducted by Coombes and colleagues (2016). As can be seen from the research reviewed, sensitivity is an essential quality of PPC, but it is typically not documented on available measures, probably because the dimensions and timeframes are not appropriate for evaluating changes occurring during PPC. Widely employed instruments in pediatrics (like the Pediatric Quality of Life Inventory [PedsQL]) have inadequate validity when used in PPC, suggesting that there are different QoL constructs in children with life-limiting illnesses and in other populations (Huang et al., 2010). A recent research program was aimed at developing a tool to measure QoL in the PPC context—the Pediatric Advanced Care Quality of Life Scale (PAC– QoL)—but it was not based on domains generated by the participants or their caregivers and thus evaluated the same traditional domains (Cataudella et al., 2014; Morley et al., 2014). As the definition of QoL may be specific for PPC and the child's status may change drastically over relatively short periods of time, there is a need to develop a new approach adapted for PPC.

In summary, while the mission of PPC is to promote QoL, the domains that QoL encompasses are still poorly defined. The traditional themes of QoL do not seem adequately specific for this population and are focused on deficits. Some studies have concentrated on a depiction of caregivers in this context, but more so on the definition of care quality criteria than on QoL itself (Andersen et al., 2004). Descriptions are made retrospectively—for instance, by bereaved parents–and do not capture the very nature of

QoL “in the here and now.” An increased awareness of caregiver representations of children’s QoL would complement the dimensions identified by previous studies and could lead to more explicit definitions. Although not exempt from bias, professionals hold a unique view on children’s status and well-being. Such a clarification of the concept of QoL in this area is a necessary preliminary step to developing a sound measurement strategy.

The objective of our present study is to identify the domains of QoL for children with cancer in palliative care according to the perceptions of professionals working in pediatric hematology/oncology. Our strategy is to help generate positive as well as negative images of QoL in order to operationalize what is meant by “quality of life” in this context. We wish to identify practical domains that can be defined precisely and utilized for further development of outcome measures.

METHODS

Our study is based on a qualitative research design that calls for a descriptive inductive analysis (Braun & Clarke, 2006; Lapierre, 1997). Based on a constructivist epistemological framework, it aims to describe the concept of QoL from the perspective of individual caregivers who are currently caring for or who have cared for a child with advanced cancer.

It is of critical importance for us to mention our background and make explicit our preconceptions to satisfy the criterion of transparency. The authors who have been particularly involved in the data analysis include a doctoral candidate in psychology at the

Centre for Psycho-Oncology at Le Centre Hospitalier Universitaire (CHU) Sainte-Justine (JAB) and her doctoral supervisors at the Université de Montréal (SS) and the Université de Sherbrooke (VP). JAB developed her clinical experience in a program targeting interventions for children and teenagers using a psychodynamic approach. Her experience in working with children with cancer has grown through volunteer activities with the Division of Hematology/ Oncology at the CHU Sainte-Justine and other organizations in the field. SS has developed an expertise in pediatric psycho-oncology as a research unit director in the same hospital, originally developing research within a cognitive behavioral orientation, and he has been recently supervising qualitative research projects using interpretative phenomenological analysis and inductive thematic analysis on grief. VP is a professor of psychology and a specialist in behavioral and cognitive disorders in children. She brings a structured lay vision to interpretations. Other of our authors have been major figures in the development of pediatric palliative care in French language countries. NH is a clinician and director of the palliative care unit at the same hospital, and MD is a hematologist/oncologist with a long experience in clinical ethics (research and practice). ML has been a postdoc working on the initial development of the research protocol submitted to the ethics committee, after achieving her doctorate in pediatric psychology. She is currently supervising a replication of the present study at the Université Catholique de Louvain (Belgium). Overall, our team was guided by an evidence-based approach. As a consequence, the literature and the components of existing instruments guided our preconceptions that participants would mainly focus on the absence of pain and symptoms to describe QoL (e.g., Lyons et al., 2009; Tomlinson, et al., 2011; Varni et

al., 1999). We also anticipated that QoL would be described within a shorter temporal perspective (i.e., weeks or days instead of months), in line with the usual clinical observation that a child's condition can change frequently and rapidly in palliative care (Coombes et al., 2016; Hinds et al., 2004).

Participants

Eligible participants were required to: be a member of the Department of Hematology/Oncology of our hospital, have cared for at least one child (18 years) with advanced cancer and treated in palliative care, and be able to speak French. A total of 20 health professionals were interviewed: 3 hematologist/oncologists, 1 psychiatrist, 5 members of the nursing staff, 2 clinical fellows, 1 nutritionist, 1 art therapist, 1 psychologist, 3 occupational therapists, and 3 physiotherapists. Participants included 17 women and 3 men, with a mean age of 41+9 years. They had been active in the hematology/oncology department for 9+7 years. No exclusion criteria were imposed.

Recruitment

We employed a maximum variation sampling recruitment strategy (Patton, 2002). Data were collected from caregivers from various professions to ensure the representativeness of different professions in hematology/oncology and data completeness. The selection of potential participants was based on the comprehensive list of the members of the department (N = 103). Each week, among three different professions, a randomly selection was doing to select three professionals were randomly selected. This random selection

was chosen to favor the inclusion of different professions and avoid bias of a-priori selection. Eligibility was confirmed during the first contact by email or through subsequent reminders. The caregivers who provided their consent were interviewed individually. Because the representations of QoL could differ from one profession to another, and because we wanted to make comparisons between them in a future analysis, we decided to include a number of participants higher than what would be normally expected in qualitative research (Patton, 2002). A total of 28 caregivers were contacted: 5 did not meet the inclusion criteria and 3 refused to participate (participation rate = 20/23, 87%). We stopped recruitment when saturation was achieved in a sample including a sufficient variety of professions in three categories: physicians, nurses, and professionals. Notably, one factor in favor of saturation was that all participants were from one and the same site. The study received ethical approval from the CHU Sainte-Justine and the University of Sherbrooke. The first author (JAB) conducted the recruitment and the interviews with participants.

Data Collection

Data were collected through individual semistructured interviews (duration = 1 hour) in which participants were asked open-ended questions according to an interview guide developed by the research team (see Online Appendix A). The questions were adapted from Hinds et al. (2004).

The interview process and agreed-upon understanding of the questions from the interview outline were approved after pilot interviews were conducted with two caregivers

not included in the final sample. During the interviews, the researcher adopted an open and empathetic attitude, trying to distance herself from prior knowledge regarding QoL and taking a step back from possible interpretive categories (Paillé & Mucchielli, 2012). At the end of the interview, participants completed a brief sociodemographic questionnaire. The interviews were recorded and transcribed verbatim for data processing.

Data Analysis

QDA Miner 4.0 software was used for coding, and the analysis was then structured in Microsoft Word to allow for greater flexibility of the analytical process. The data were analyzed inductively according to the thematic analysis approach (Braun & Clarke, 2006; Paillé & Mucchielli, 2012). First, the principal investigator became acquainted with the data by transcribing and rereading the interviews. Then, according to a continual thematization process, the meaning of the text to be analyzed was extracted from each transcription by identifying codes in the margins (coding). The inventory of these codes was systematically created in a separate document (list of codes). From this list, we created the thematization journal, in which a systematic process of code identification, consolidation, integration, subdivision, and hierarchization was performed as the data were collected. During the analysis, the themes were refined, clarified, and specified by rereading the interviews, through discussions and exchanges among the researchers, and by resorting to an external expert specialized in this approach. The themes were then hierarchized in the form of central themes in order to gradually build a synthetic and structured representation of the analyzed context (thematic tree). Finally, we proceeded to

nomination and definition of these themes to describe a representation of QoL (Paillé & Mucchielli, 2012).

To ensure the rigor of our analysis, we employed recommended methodological strategies (Mays & Pope, 2000; Whittemore et al., 2001). To ensure the reliability of our study, we used a reflexive journal to record all steps and decisions made during the analysis. The coding of transcripts was performed by the first author (JAB) and checked by her supervisors (SS, VP). Consensus was sought in case of divergence. To ensure a sound application of the method, we called for an external qualitative analysis expert (MC, see acknowledgments). On two occasions, she checked our compliance with the rules of the analysis and provided corrective advice. To ensure the credibility criteria, triangulation was utilized by collecting the perspective of participants from various professions. We also validated the methodological approach by way of a feedback discussion on preliminary findings to the hematology/oncology department and at PPC/psycho-oncology congresses. Throughout the analysis, we discussed and exchanged information on coding of transcripts and thematization within the research. In this process, as recommended by the authors of descriptive inductive analysis (Braun & Clarke, 2006; Lapierre, 1997), specific attention was paid at all steps to the convergence and divergence of themes during their progressive definition.

RESULTS

Following the analysis, seven domains were identified to describe caregivers' perceptions of QoL in PPC in oncology: (1) physical comfort, (2) alleviation of psychological

suffering, (3) fun and the present moment, (4) sense of control, (5) feeling valued and appreciated, (6) feeling that life goes on, and (7) meaningful social relationships. The final thematic tree is depicted in Figure 1.

Physical Comfort

All participants mentioned this domain as an important aspect of QoL. Mainly described by the absence of pain or symptoms or by the relief of both, physical comfort is also characterized by the satisfaction of such physical needs as getting enough sleep, breathing properly, or eating without choking. Comfort is a necessary aspect of QoL, but it is not considered sufficient by caregivers.

Alleviation of Psychological Suffering

QoL is also characterized by a state of alleviation in which the cognitive symptoms (e.g., hallucinations, loss of consciousness) and psychological symptoms (e.g., anxiety, psychological distress) associated with the medical condition or perceived limitations are adequately controlled.

Fun and the Present Moment

This theme highlights the increasing importance of fun and being in the present moment for the QoL of children with advanced cancer. Professionals speak of “being in life” to describe how important it is for the child to experience fun at times when he or she is not anticipating the end of life but is rather able to enjoy the present moment:

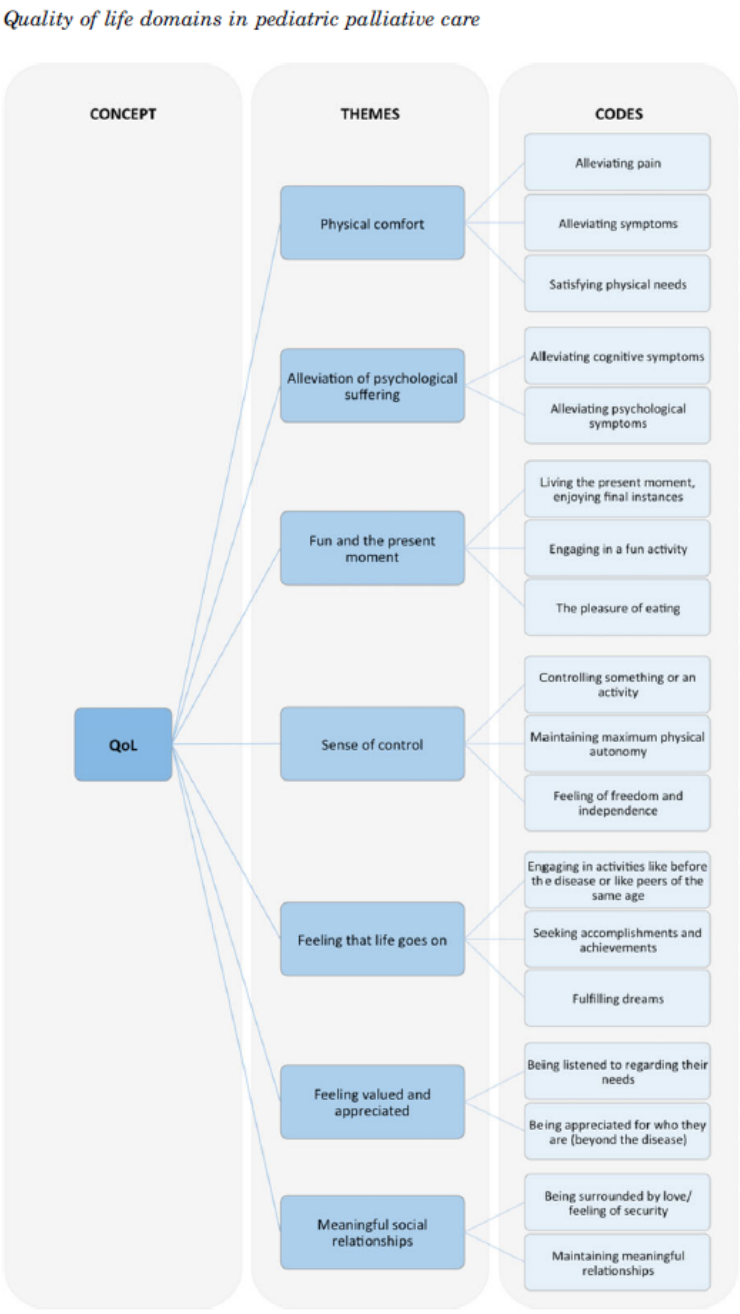

Fig. 1. Quality of life definition and domains as reflected by professional caregivers' views in pediatric oncology.

P4: For now, I think his quality of life is high. It's good precisely because they are very much in life, having fun and enjoying it.

Fun would be reflected in daily life through activities the child likes to do or through the presence of small instantaneous pleasures:

> P7: I have a little guy in mind. Well, maybe it's playing with his trucks [...] to be read a story by mom on her lap. Maybe it's simply to make soap bubbles. Maybe it's to be able to dress up as a princess. What does a child like to do? To play, to laugh [...] it can be very small joys, as small as going outside in a stroller, it can be as small as to just be sitting in bed and having friends over. It can be as small as just having a hand stroked.

Food also plays a crucial role from the perspective of the caregiver. Despite the fact that the disease and treatment often affect nutrition (dietary restrictions, chewing difficulties, stomach problems), some professionals have witnessed moments where the pleasure of eating appeared to be prominent in the child they were caring for:

> P8: I saw several children at the end of their lives for whom their pleasure was to eat. [...] There are children, I swear to you, who love to eat and whose dream is really to have a big meal prepared by their mother and to eat that during the last weeks of ...

Sense of Control

According to the professionals, a part of QoL is linked to the feeling children have of controlling aspects of their daily life and their environment. Many caregivers reported that being in control of a situation, like being able to partake in their own care, is a crucial aspect of their QoL:

> P3: We took the opportunity, when he was better, to have him partake as much as possible in his diaper change [...] keeping him active as much as possible in his activities of daily life, too.

Similarly, the loss of physical autonomy is pervasive, especially in older children and teenagers. Young individuals often find themselves confronted with functional losses resulting in amputations, paralysis or a lack of energy that prevent them from performing tasks without assistance. The professionals reported that the QoL of these young

individuals is characterized by their ability to do things on their own so that they can maintain as much physical autonomy as possible:

> P7: It's the fact of going on his own. So, for him, he would go with someone, but it wasn't, he wasn't required to go with daddy, mommy, or things like [...] So, he would go with all his independence, and he was the one to make the decisions, and so on. He had brought his money, and he paid for his meal. That had been really, really interesting.

These young individuals are also dependent on the care provided by their relatives, which undoubtedly affects their intimacy and freedom. It is therefore essential for their QoL for them to be able to experience moments of independence by having the freedom to make decisions and to do what they want to do.

Feeling Valued and Appreciated

Quality of life was here associated with the feeling of appreciation the child can experience and the feeling that he or she is being valued and considered as a person, beyond his or her deficits and the difficulties linked to the disease. The fact of being listened to and respected along with his or her needs and desires is also a central aspect of this theme:

> P7: [...] the quality of life, it would be to be appreciated for who he was. To say his name and to not see him for all that he was missing, but for who he was. I would say that was his quality of life.

Feeling that Life Goes on

This theme refers to the maintenance of daily activities "like before the disease," and to the aspiration to accomplish or achieve dreams despite the limitations caused by the disease, such as fatigue and pain. The professionals described a sense of normalcy by

stressing the importance children attribute to maintaining activities they used to participate in before the disease or that children of the same age do:

> P16: I think that at some point, too, not being at home anymore, she had been to the movies, well with the wheelchair and everything, with a friend or a couple of her friends and mom was probably there. [...] To have an activity like kids her age [...] I think all of that was like, "Wow, I was able to go see this movie, even though I was in a wheelchair!" And, you know, like eating popcorn. [...] Anyway, I remember that she was very very happy. But I think it's the fact of doing things of her age and to see the movie of the year, of that summer.

Self-actualization and the fulfillment of personal projects also constitute an important aspect of the QoL of young persons in PPC: pursuing secondary education, doing handiwork, being able to sit up in bed:

> P6: The best days were the days when he was able to say that he had achieved something. It was much less than what he was able to achieve before. It could be an outing. I'm thinking of the time he went to go see the Canadians [Montreal's hockey team]. It can be simpler things than what he would do before, but to have achieved something.

Thus, vitality is an essential aspect of QoL. Although the nature of the achievement can vary from child to child, it is the inner feeling gained that is important for QoL. Finally, these children still need to dream about projects that stimulate them. Thus, the possibility to daydream, to live out a childhood dream, and to have desires also characterizes their QoL.

Meaningful Social Relationships

> P12: In quality of life, there is also the family environment. There are children who are lucky to have amazing support from their family and very attentive parents [...] siblings who are very involved and who play an important role.

Maintaining meaningful relationships with those around him or her is also considered essential to QoL. When caregivers were asked to say what they thought was the most important for the child they were caring for in PPC, most stated that it seemed to be the fact of being surrounded by his or her loved ones: parents, families, and friends, but also the caregiving staff.

DISCUSSION

Our study found a descriptive model of QoL in the context of PPC based on the views and experience of professional caregivers from a hematology/oncology department. This model distinguishes itself as previous studies have primarily focused on the perspectives of children and parents (Barrera et al., 2005; von Lützau et al., 2012; Friedrichsdorf et al., 2015; Hechler et al, 2006).

The first three themes—"physical comfort," "alleviation of psychological suffering," and "meaningful social relationships"—are consistent with the physical, emotional, and social dimensions usually utilized to conceptualize QoL and are present in all QoL assessment tools utilized in pediatric oncology (Coombes et al., 2016; Pépin et al., 2015). That the caregivers recalled these dimensions highlights the fact that in the palliative phase of cancer, as at other points along the disease trajectory, the central aspects of QoL are the alleviation of disabling symptoms and pain, treatment of emotional distress, anxiety, and sadness, and maintaining meaningful social relationships that contribute to a sense of affiliation and the need for love and security.

In addition to social ties with family and friends, our results also bolster the importance of fostering meaningful relationships with professionals. Particular attention was paid by participants to the impact of interpersonal communication on children's QoL. The role of communication between children and their parents has been described previously (Barrera et al., 2005). In our study, the role of communication with professionals and within the professional team was particularly underlined. Inconsistency among team members was cited as a factor that negatively affected children's QoL.

In addition, our professional caregivers reported four other themes that are rarely mentioned or not listed at all in the literature of QoL in PPC as perceived by children and their parents: "fun and the present moment," "sense of control," "feeling valued and appreciated," and "feeling that life goes on." These themes are positively formulated and based on positively worded transcripts. This differs from the usual portrayal of QoL from previous studies in which indicators are generally related to deterioration of health, limitations, or deficits (Knapp et al., 2012; Tomlinson et al., 2011).

First, the "fun and the present moment" theme focuses on the presence of short pleasurable moments and the ability to live in the present moment. In addition to confirming the relevance of focusing on the child's degree of pleasure or on enjoyable family activities as previous studies have done (Barrera et al., 2005; Friedrichsdorf et al., 2015), our caregivers' discourse explains that the child's QoL depends on his or her ability to remain rooted in the present moment. This input also emphasizes the need to be sensitive to a child's sense of satisfaction with regard to his or her expectations and desires. It is interesting to note that caregivers' examples were always specific and focused

within a short temporal perspective. The professionals spoke of “moments” and “days”—the envisioned perspective was never that of a month, as it is in the tools adapted to other contexts (e.g., PedsQL).

The theme “sense of control” attests to the caregivers’ concerns regarding the pervasive influence that loss of autonomy and a sense of freedom has over a child’s QoL in PPC. Although autonomy is a central aspect in many QoL models, the very concrete examples and suggestions given by professionals to foster and maintain autonomy in children constitute something new. This suggests that professional teams can do a lot on this topic. This is all the more important since caregivers believe that the perception of control also serves to offset deterioration of health. It is beneficial for a child’s QoL to favor this sense of control by allowing them to partake in care decisions. This theme is relevant to the child’s life potential in relation to his or her current abilities and again contrasts with the tendency to evaluate a child’s QoL solely based on deficits (Knapp et al., 2012).

The third theme, “feeling valued and appreciated,” is rarely mentioned as a component of QoL in the literature. It mainly echoes an appreciation of the individuality and subjectivity of a child’s experience with respect to his or her QoL. Our professionals mostly referred to concrete actions that should be taken to favor a child’s QoL. Beyond the few examples given, it is possible that this theme is particularly influenced by the norms of patient-centered care that are often discussed in oncology. It is recommended to provide respectful care that has an affinity for a patient’s personal preferences, needs, and values, and to ensure that the patient’s values guide clinical decisions (Institute of Medicine, 2001).

Finally, with regard to the theme “feeling that life goes on,” our results suggest that it is particularly important for the child to continue to engage in the activities he/she performed before, despite the symptoms and losses associated with the course of the disease. This is consistent with the results of multiple studies which showed that fatigue is one of the most common symptoms and one of the most poorly supported for children throughout the cancer trajectory, particularly when it is longlasting (Barsevick et al., 2013). Having the opportunity to engage in activities allows them to feel alive. The maintenance of activities is also related to a quest for normalcy vis-à-vis the child’s peers, but also with respect to him or herself. This theme is in line with transcripts obtained from children and parents on maintaining normalcy (Barrera et al., 2005; Kamper et al., 2010). The members of the medical team emphasized the importance of a sense of accomplishment and achievement of dreams for a child’s QoL. Having the opportunity to experience small accomplishments or to live out a dream can certainly provide hope and strength during this time of hardship, a component that has been associated with QoL in previous research (Barrera et al,. 2005; Cataudella et al., 2014; Morley et al., 2014).

One of the explanations for the differences between the themes identified in our study and those from previous research (e.g., Barrera et al., 2005; Cataudella et al., 2014) is that we collected caregivers’ perspectives. It is possible that the positions of the professional caregiver affords some degree of objective separation that could make it possible for certain themes to emerge more clearly. While children are often in a difficult position when it comes to articulating their QoL, caregivers are in the powerful position of being able to put the experiences of the child into words. Of course, this implies a high degree

of responsibility, as such perceptions can be biased by one's own impressions and/or misunderstandings. Another reason is that, in contrast to the establishment of the PAC–QoL dimensions, which relied on a literature review and expert panel discussions (Cataudella et al., 2014; Morley et al., 2014), our dimensions were determined inductively by the participants themselves. We attempted to disregard prior assumptions in our research process. Thus, the description of QoL offered herein is based on caregivers' experiences rather than on domains defined a priori.

An important notion that emerges from our study is the specific and individual nature of a child's QoL. Most professionals were conscious of the limitations of their position. They strongly held that the professional caregiver is only one of several informants on the child's status, but that the best informant is most probably the child him/herself. These results are in line with the utmost precision required in the clinical context, as various authors have showed that the trajectory, the stage of disease development, and the type of cancer should be taken into account in the assessment of QoL (Tomlinson, 2011; Varni et al., 2007).

A final important idea that emerges from our results concerns the limited timeframe to be considered when conceptualizing QoL in the context of pediatric palliative care. This presents several advantages, such as focusing on daily activities or achievements and thus providing a greater opportunity for expression of positive life events instead of limitations and/ or losses. Moreover, children who receive PPC often have frequently changing symptoms, which can itself affect their QoL. At the same time, a reduced timeframe makes it more possible to evaluate individual changes (Coombes et al., 2016). In other words,

focusing on short periods of time increases the evaluator's sensibility regarding the variability of QoL over time. Particularly in pediatrics, children and adolescents are known to use different markers to elaborate the concept of time, and such markers change over the course of their development (Michel et al., 2012; Rebok et al., 2001). This would probably make a longer timeframe more valid in older children. Shorter recall periods (i.e., 2 days) have already been used with success in some pediatric disease-specific measures (e.g., the Memorial Symptom Assessment Scale [MSAS], Collins et al., 2002).

LIMITATIONS AND IMPLICATIONS OF THE STUDY

One limitation of our study is its sample. Even if the themes concern children's QoL, they were not identified by interviewing children and their families, and therefore cannot be put forward as representing the child's point of view. However, the perspective of professional caregivers is particularly important in cases where a multi-informant strategy is employed. Updating professionals' representations of the QoL of children they care for in PPC can foster better communication and enhanced consistency within the care team. In addition, although we tried to meet caregivers from different professions, the sample allocation was not representative of oncology staff. It is possible that this introduced biases in the frequency of certain codes, but it is unlikely to be reflected in the thematic categories, since categories were not determined on the basis of frequency. Finally, the interview guide (Hinds et al., 2006) encouraged a shorter timeframe through questions about good/bad days. However, it should be noted that a large proportion of professionals spontaneously described QoL according to a greatly reduced timeframe, associated with

the present moment, which is far shorter than that proposed by interview questions focusing on "a good day."

Despite these limitations, our research could have important implications. In practice, professionals could share and exchange ideas related primarily to the identified themes and delineate avenues for improving QoL using this framework. In the research framework, one could present the findings to children and parents in PPC and get their impressions by using, for example, a participatory action research model. This would test the robustness of our present findings and foster development of a practical evaluation strategy for the validated themes. The identified components of QoL could lead to a better assessment of QoL according to the trajectory of a child with advanced cancer by allowing for the creation of a rating scale. Recent research has asserted the lack of outcome measurement in PPC (Coombes et al., 2016). Exchanging details on these components would help identify targets for individual progress, involving many aspects of care—for example, providing comfort by changing a child's position in bed or by giving the child an opportunity to draw or write.

CONCLUSIONS

Our study offers a model of how professionals who have cared for children with advanced cancer in PPC conceive of QoL. Based on a descriptive inductive analysis of interview transcripts, we found three themes already present in the literature: "physical comfort," "alleviation of psychological suffering," and "meaningful social relationships." Our professional caregivers suggested four new themes: "fun and the present moment," "a

sense of control," "feeling valued and appreciated," and "feeling that life goes on." Future studies should explore these dimensions in children and their family members, which could help develop practical assessment tools to measure quality of life in the context of pediatric palliative care.

DISCLOSURES

The authors hereby state that they have no conflicts of interest to disclose.

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APPENDIX A

Semistructured Interview Guide

1. Exploring the professional's experience in hematology/oncology with children in palliative care.

   Question

   - Have you encountered children suffering from cancer and receiving palliative care? If you had to quantify your experience, how many such children have you encountered in the last 12 months?

   - Can you recall one of these children specifically?

   - What types of services did you provide him or her with? For how long? How often?

   - Could you briefly describe the type of relationship you had, as a caregiver, with this child that you knew in palliative care?

2. Identifying the professional's perceptions of the child's QoL
   Purpose: Indirectly itemize the components of QoL as perceived by the caregiver.

   Questions
   Still recalling this child.

   - According to you, what was it that made this child have a good day? A bad day? A good time? A bad time? Do you remember one of those moments? (Identify and explore the elements adduced by the participant to meet his/her perception of the components influencing the child's good/bad day and good/bad time.)

   - In your opinion, what was most important for this child in palliative care?

   - Now, if we think more generally, what do you think defines a good day for a child with advanced cancer in palliative care? And what defines a bad day?

3. Identifying the professional's perceptions of the child's QoL and activities or trends involved in defining a good or bad QoL for the child.
   Purpose: Itemize, with more concrete questions, the components of QoL as well as those influencing the child's QoL as perceived by the caregiver.

   Questions

- Could you describe the QoL of the child for whom you provided care to?

- If we think more generally about children with cancer in palliative care, what would be the criteria to consider in the evaluation of their QoL?

- Finally, what would be your definition of QoL in pediatric palliative care? Is there anything else you would like to add concerning the QoL of children with advanced cancer in palliative care?

Is there anything else you would like to add concerning the QoL of children with advanced cancer in palliative care?

Chapitre II

How do professionals assess the Quality of Life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement?

How do professionals assess the Quality of Life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement?

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ABSTRACT

Background: It is known that information regarding the quality of life of a patient is central to pediatric palliative care. This information allows professionals to adapt the care and support provided to children and their families. Previous studies have documented the major areas to be investigated in order to assess the quality of life, although it is not yet known what operational criteria or piece of information should be used in the context of pediatric palliative care. The present study aims to **:** 1) Identify signs of quality of life and evaluation methods currently used by professionals to assess the quality of life of children with cancer receiving palliative care. 2) Collect recommendations from professionals to improve the evaluation of quality of life in this context.

Methods: We selected a qualitative research design and applied an inductive thematic content analysis to the verbal material. Participants included 20 members of the Department of Hematology-Oncology at CHU Sainte-Justine from various professions (e.g. physicians, nurses, psychosocial staff) who had cared for at least one child with cancer receiving palliative care in the last year.

Results: Professionals did not have access to pre-established criteria or to a defined procedure to assess the quality of life of children they followed in the context of PPC. They reported basing their assessment on the child's non-verbal cues, relational availability and elements of his/her environment. These cues are typically collected through observation, interpretation and by asking the child, his/her parents, and other members of the care. To improve the assessment of quality of life professionals recommended optimizing interdisciplinary communication, involving the child and the

family in the evaluation process, increasing training to palliative care in hematology/oncology, and developing formalized measurement tools.

Conclusion: The formulation of explicit criteria to assess the quality of life in this context, along with detailed recommendations provided by professionals, support the development of systematic measurement strategy. Such a strategy would contribute to the development of common care goals and further facilitate communication between professionals and with the family.

Keywords: Pediatric palliative care, Quality of life, Measurement, Pediatric cancer, Qualitative study

BACKGROUND

Cancer is responsible for 20 to 30% of cases of children in palliative care [1-3]. Pediatric palliative care (PPC) consists of active and comprehensive care designed to prevent and alleviate suffering and improve the quality of life (QoL) of children and their families [e.g., 4, 5, 6].

QoL is therefore at the heart of palliative care and is generally described as multidimensional and subjective [6, 7]. The physical, emotional and social aspects of QoL are the most frequently studied [8, 9]. In the specific context of PPC in oncology, recent studies of children with advanced cancer and their parents have revealed that the physical well-being of children is an inherent part of their QoL. Losses and symptoms caused by the disease on the child's overall functioning are of great importance in this respect [e.g., 10]. In addition, more and more studies have highlighted the positive components of QoL, such as maintaining a child's sense of normalcy and everyday pleasures [e.g., 11, 12-14]. Importantly, spiritual dimensions have recently been studied in children and include such themes as maintaining hope and finding meaning in life [e.g., 11, 15]. In an earlier study on professionals who accompanied children in palliative care, we found unique positive dimensions to define the child's QoL such as having fun and focusing on the present moment, feeling valued and appreciated, maintaining a sense of control and feeling that life goes on [16].

In oncology, care is focused on both children’s survival and on their overall comfort. Assessing QoL is thus particularly important as it contributes to therapeutic decisions and

is useful in improving patients' overall care [e. g., 4, 17, 18]. Several measuring tools have been developed in recent decades to assess the QoL in pediatric oncology [19-21]. However, these strategies rely heavily on coding or reporting the presence or absence of symptoms or complaints [22]. These are usually scales where the child (self-reported version) or his/her parents (proxy version) are the primary respondents [23, 24], but because these tools are focused on periods of curative treatment, they miss important topics that are specific to children with PPC.

In fact, a systematic review of the literature was recently carried out to determine whether the existing measures of QoL could be applied to this population in palliative care. The results indicate that none of the existing measures in oncology would meet the criteria for adequate use in PPC [19]. The PedsQL 4.0 for instance, which is the most widely used tool for measuring QoL in oncology, has been shown to bear shortcomings for this population as a result of inappropriate items that do not take into account the physical limitations of children in palliative care [25]. Measures of QoL do not always incorporate a temporality that is fitting for PPC, where it is recommended to focus on shorter periods of time (e.g. daily assessment) to increase the evaluator's sensitivity to the variability of the child's status over time [16].

In summary, the current tools do not specifically assess the QoL of children with advanced cancer who receive PPC as they do for young patients during treatment or in after-care [19, 25-27]. It has been recommended by different authors that QoL measures be developed to reflect the reality of children with a life-threatening disease [19, 26]. A

tool was recently developed on the basis of areas of QoL that had been identified previously [26], but the measure is lengthy (57-65 items per version).

Considering the central importance of QoL as a target in PPC, it is noteworthy that no adequate, accurate and valid instrument is available to date. Although we may expect that professionals use their own judgments to assess the QoL, we do not know what information they use in clinical practice or how they proceed to form an opinion about the QoL of a child. One strategy to address this issue is to obtain input from professionals who have experience with these children. We need to identify how professionals evaluate the QoL of children and what are their suggestions for improving this evaluation [28].

The aim of the study is to explore and describe how professionals evaluate the QoL of the children with advanced cancer receiving PPC and what they recommend to optimize the evaluation of QoL in this area. The specific objectives are 1) to identify which signs or cues and evaluation methods are used by professionals in hematology-oncology to evaluate the QoL of children with advanced cancer receiving PPC and 2) to collect recommendations of professionals to further optimize this evaluation.

METHODS

The present study focuses on the second part of an interview taken by professionals in hematology-oncology as part of a study to define the domains of QoL in PPC [16]. The present study is based on an inductive qualitative research method within a descriptive constructivist epistemology [29, 30].

Participants

The participants were 20 health professionals: 3 hematologist-oncologists, 1 psychiatrist, 5 nursing staff members, 2 clinical fellows, 1 nutritionist, 1 art therapist, 1 psychologist, 3 occupational therapists, and 3 physiotherapists. All were selected on the basis of the following criteria: they had to be a member of the Department of Hematology-Oncology of our hospital, have cared for at least one child (≤ 18 years) with advanced cancer receiving PPC, and speak French.

Recruitment

The study received ethical approval from the CHU Sainte-Justine Research Ethics Committee (3547) and the University of Sherbrooke Research Ethics Committee (2013-1245). Data were collected by using maximum variation sampling recruitment strategy from professionals with diverse roles [31]. The selection of participants was based on the comprehensive list of members of the department (N = 103). To include different professions and avoid bias of a priori selection, a random selection was made each week to select three professionals across three different professions (physicians, nurses, other professionals). A total of 28 professionals were contacted, among whom 2 participated to a pre-test to refine interview strategies. Among the remaining 26, 23 met the inclusion criteria and 3 refused to participate (participation rate: 20/23 87% for the present analysis). The recruitment was stopped when saturation was attained across these three groups of professions. Written informed consent was collected from the participants during the initial interview. The recruitment and the interviews with participants were conducted by the first author (JAB).

Data collection

Data collection took place from March 7, 2013 to April 2014. Individual semi-structured interviews (average duration of 1 hour) were performed to collect data. The interview guide developed by the research team was inspired by Hinds et al. (2004) (see additional file 1). The present analysis focuses on verbal material collected in response to questions specifically aimed at signs and evaluation methods used by the professionals to assess the QoL of the children in the context of PPC, and the professionals' recommendations to optimize this assessment. Participants also completed a brief sociodemographic questionnaire. The interviews were audio recorded and transcribed for data processing.

Data analysis

Data were analyzed inductively according to the thematic analysis approach [29, 30]. As outlined in the first report [16], data were analyzed according continual thematization process and a thematization journal were used. That way, each transcript was coded according to the two aims of the present study (aim 1: signs and evaluation approaches of QoL; aim 2: recommendations to optimize the QoL assessment). Two lists of codes were made and the process of code comparison was performed for each of these lists. The first themes were created with the aim of maintaining a low level of inference in order to respect the participants' statements as much as possible. Thematic clusters have thus gradually taken shape and highlighted signs and evaluation methods mentioned by the professionals on the one hand (aim 1) as well as their recommendations to optimize the assessment of QoL (aim 2) on the other. A synthetic and structured representation of

each of the thematic clusters was then constructed according to the two aims of the study. The analysis was carried out by hand using Word to allow greater flexibility in the analysis process. The saturation of data was attainted.

Various recommended methodological strategies were employed during the analysis [32, 33] including the systematic use of reflexive journal, triangulation, discussions and exchanges among researchers and feedback meetings with members of the hematology-oncology department. Also, by using a bottom-up process to identify the themes - which helped include comprehensive categories with higher levels of inference - we were able to ensure better validity of the results, as the emphasis from the outset was placed on the participants' responses rather than on a simple classification.

RESULTS

The results highlight that professionals involved in this study do not have access to pre-established criteria or to a defined procedure that they can rely on. They were rather guided by their observations and clinical judgment.

Aim 1. Description of signs and evaluation methods used by professionals to assess the QoL of the children with advanced cancer receiving PPC.

Thematic analysis produced three themes for signs that inform the professionals about the QoL: (1) non-verbal cues and the relational availability of the child; (2) indicators specific to domains of QoL; and (3) indicators specific to the child's life context.

Non-verbal cues and the relational availability of the child. Non-verbal cues and those linked to the child's relational availability allow professionals to form a basic idea of the child's current overall state. Table 1 presents examples of non-verbal cues and relational availability reported by participants.

Table 1. Examples of non-verbal cues and relational availability to observe the quality of life

Positive	Negative
· Smiles · Laughs · Better eye contact · Bright-eyed · Relaxed facial features · Relaxed body and breathing rhythm · Is awake for longer periods of time · Responds more to questions · Accepts and participates more in care · Chats more and shows a desire to interact with the environment · Is more involved in activities · Engages in his/her occupations and plays	· Absent gaze · Avoids eye contact · Frowns · Body tension and restless breathing · Has difficulty calming down · Is agitated, screams, cries · Self-mutilation · Is closed off · Is curled up in bed · Appears discouraged · Responds to questions sparingly or not at all · Refuses to see professionals and to receive care · Diminished relational availability · Irritability · Sleeps most of the time

" […] she was suffering and you could tell by the way she was breathing and by the position of her body, in her shoulders, her arms, the fact that she was curled up, the fact that she was tense, that her face was stiff, her breathing more superficial." P11

" I saw her smile and happy from our exchange, and she made me a little heart [on a paper], you know, she wanted to show that she was happy to feel connected. […] Otherwise, when she was not doing so well, there was no connection or empathy that could be felt or shared." P4

Indicators specific to domains of QoL. QoL is also considered to be the result of an evaluation involving different spheres of the child's life. Professionals refer to previously identified areas in an operationalized way: Physical comfort, Psychological alleviation, Fun and the present moment, Sense of control, Feeling that life goes on, and Meaningful social relationships [16]. For example, in "Fun and the present moment", games are an essential criterion. Additional file 2 includes examples of signs associated with each of the dimensions of QoL.

" We'll split up [the evaluation of QoL]: "Well, there is pain relief, is he okay? Yes perfect. Nutrition? Yes perfect… Does she play? Does she have fun?" In the end, it all revolves around their QoL" P20

Indicators specific to the child's life context. Finally, most participants also mentioned taking into account signs related to the living context of the child and his/her family. These elements help professionals give meaning to other perceived signs that have been detected in the areas of QoL. The sub-themes of this theme are the individual characteristics of the child, his or her medical and care history, family dynamics, and the characteristics of his or her living environment. These aspects of the child's environment

helps contextualize and better understand the child's QoL. Additional file 3 includes description and examples of indicators specific to the child's life context.

Interestingly, part of the professionals' responses focused not only on the signs themselves but on ways of accessing the signs of QoL. Subsequent to the coding work, we classified these evaluation methods into 4 themes: (1) Observation; (2) Direct investigation; (3) Interpretation; and (4) The use of diverse informants.

Observation. All participants referred to the observation approach, which allows professionals to identify non-verbal cues, the child's relational availability, his or her life habits, the presence of visible symptoms or lack thereof, and contextual aspects such as the characteristics of the child's physical environment. The observation examples reported by participants help describe this approach as a process of intentional attention directed towards the child's and family's discourses and daily non-verbal cues.

" I remember once he had celebrated his birthday and when he would talk about it, he was all smiles and, you know, he'd often be more tired and have more difficulty speaking, but when he spoke of events that had made him happy like that, it wasn't even a big activity, really, but he had truly had fun. He would talk about it and smile […] his eyes would light up." P16

Direct investigation. Most professionals explained that they also gather information about the child's QoL by asking the child, parents or professionals simple and direct questions. Professionals also refer to their notes and reports on file, as well as tools to assess specific areas of QoL such as physical well-being through pain assessments.

"[…] we would ask him: "Are you in pain?", he was able to answer. So we could have that information […] he couldn't elaborate on it, but…Simple questions, you know: "Are you hungry? Are you in pain?", he could say yes or no." P1

Direct investigation is an evaluation method that allows professionals to validate their first clinical impressions based on their observations and to deepen and validate their understanding of the child's well-being and that of those around him/her.

Interpretation. Professionals also described the use of two types of interpretation: interpretation based on self and interpretation based on other. Interpretation in this context is a process through which professionals estimate QoL from a preliminary gathering of cues via observation or direct investigation.

Interpretation based on self. This sub-theme describes the appraisal of the child's QoL based on the professional's own points of reference and understanding. It consists of a normative judgment on the QoL of the child treated with PPC.

" I think that, sometimes, health professionals are misguided to speak, to qualify a good or bad quality of life because for them, it would not be a good quality of life." P14

Interpretation based on other. In contrast, it is an approach that encourages imagining the child's perspective, putting oneself in his or her place to understand and anticipate his or her own subjective QoL. This process comes from an intentional openness to understanding how the other may feel. Participants mentioned this form of interpretation mainly in cases where direct communication with the child was restricted.

" I try and imagine the child's perspective…What brings them joy, but are no longer able to do, well I imagine that it has a big effect on their quality of life." (P5)

The use of diverse informants. The analysis of the participants' responses highlights that most of the professionals have used the perspective of several informants to document the QoL of the child they cared for. This process allowed them to collect richer and complementary information on the child's QoL.

"[…] when we carry out an evaluation, we look for as much information as possible, but from different people. That means, we'll seek out the perspective of the medical team, of the parents, and if we can ask the child, we'll question the child." P1

From this perspective, all participants mentioned the specific and individual nature of each child's QoL and several insisted that the best informant is first and foremost the child him/herself. Great importance is also attributed to the opinion of the parents, who often provide a glimpse into the child's inner world. Indeed, their perspective is deemed essential, especially when communication with the child is hampered by a disability or restricted because of his or her young age. Furthermore, the evaluation of QoL is reported to be more precise and accurate when the opinions of other professionals involved with the child's care are collected.

In short, the content of the participants' responses indicates that in clinical practice there is actually no planned and systematized evaluation of QoL. The approach is rather left to the professional's discretion. Figure 1 illustrates an overview of the signs and ways used by professionals to assess the QoL of children they care for. This underlines that

children's QoL evaluation is complex and requires a combination of indicators, as well as a multi-source strategy to allow professionals to form an overall picture of QoL.

Aim 2. Recommendations of professionals to further optimize the evaluation of QoL.

In this part of the interview, the health professionals mentioned several tips to improve the assessment of QoL. These tips are summarized in 4 themes: (1) promote communication among members of the health care team; (2) focus the assessment on the child's needs, the family, and involve them in the assessment process; (3) use of a formal tool to assess the QoL; (4) develop training that is specific to PPC in oncology. Table 2 summarizes the recommendations resulting from the analysis of the content of the participants' responses.

Table 2. Professionals recommendations to improve the assessment of QoL

Recommandations	Sub-themes
Promote communication among members of the health care team	· Hold multidisciplinary meetings · Communicate beyond the notes on file · Collect the opinions of a meaningful professional · Involve the palliative care team
Focus the assessment on the child's needs, the family, and involve them in the assessment process	· Be attentive to the needs and desires of the family · Involve them in the assessment process
Use of a formal tool to assess the QoL	· Use standardized tools in the assessment of the dimensions of QoL · Create a formal measure of QoL in PPC in oncology
Develop training that is specific to PPC in oncology	· Become familiar with the context of PPC in oncology through training

Promote communication among members of the health care team. The professionals suggested that team meetings be held frequently and that the team put together a compilation of key information for the meaningful use of professionals. The involvement of the PPC team is also mentioned as a factor that is conducive to communication, as it helps refocus aims and establish new points of action. It was also recommended that specific moments of exchanges take place, beyond simply discussing file notes.

" What's important is that everyone, even if we have our own perspective, that we manage to put it all together. So even if we do it individually and don't look at the same aspects, in the end, it's helpful because we will not forget the different aspects, but we have to make sure to bring back all these aspects to the team to focus on what the priority should be and ensure that no aspect has been forgotten." P20

Focus the assessment on the child's needs, the family, and involve them in the assessment process. The involvement of the patient and his or her family, both at the time of the assessment of QoL and in the multidisciplinary meetings, has also been described as a lever that helps create the assessment according to the families' needs, while ensuring the validity of the assessment.

" […] we need to focus on the family's needs. I may not agree with what the family or what my colleague would like for that child, but if the family says: "This is our priority." Well, that's what we need to focus on. […] Because if you just come in and say this is how we're going to do things, but that it does not meet their needs, we'd be doing all that for nothing.

So even if that's not what we would have prioritized, if the family says: "This is what I want to prioritize.", well that's what we have to do." P20

Use of a formal tool to assess the QoL. Professionals spontaneously mentioned the value of using an assessment tool that is specific to measuring the QoL of children with PPC, although none had ever used a formal tool or procedure in this context before.

" […] I think that right now, everyone is sort of using their intuition. And, we don't really have any markers. You go with your intuition and according to the needs you see. […] we don't have any tools…It's really very intuitive…" P18

The use of such a tool would provide a common reference point to facilitate communication between patients and professionals, and among professionals of different professions in order to promote agreement and communication.

" I think that it's an aspect that isn't developed enough... it should be part of the basic stuff, just as important as a pain assessment. Relying on something that's already out there or to come up with a new standardized test…so as to be able to quantify it and so that everyone agrees on the same system, on the same way of doing things to go in the same direction and perhaps improve his or her QoL." P2

Develop training that is specific to PPC in oncology. The use of training that is specific to palliative care and to children with terminal cancer or who are not responding to treatment is a way for professionals to be better informed on the context, its challenges, alternative interventions, and approaches that should be favored in these difficult clinical

situations. Indeed, this deeper awareness would help them better understand, evaluate, and improve the QoL of the children and their families.

" I think it needs to be improved perhaps by doing a little more staff training, because I really find that there isn't a lot of training. And as for the health professionals, we are not necessarily certified. […] it is currently something that is needed, but that we do not have." (P9)

DISCUSSION

This study focuses on signs and evaluation methods of the QoL of children with advanced cancer as reported by professionals, and their recommendations to improve the assessment of QoL. Following the interviews, which we analyzed inductively using a qualitative method, we created a descriptive model that reveals the difficulty of this evaluation in current practices. Our results particularly highlight the importance of collaborative work among the multidisciplinary team members and the need for sharing and collaborating with the children and their family.

Main findings

Signs and evaluation methods to assess the QoL. Based on our findings, the professionals involved in this study do not have access to pre-established criteria or to a defined procedure that they can rely on to assess the QoL of the children they follow in PPC. They are rather guided by their observations and clinical judgment.

With respect to the signs they mentioned, we can draw a parallel within the main areas of QoL (physical, psychological and social) [8, 9]. For example, professionals refer to factors such as pain levels, emotional distress, and whether the child has a supportive network. However, unlike items that are usually listed in the currently available measures of QoL, which are generally focused on deficits [22, 23], professionals reported indicators of QoL that focus on joyful moments, on anchoring oneself in the present moment, and on the pursuit of small daily accomplishments. The emphasis here is on the child's current opportunities, in addition to his or her limitations. The spiritual component of quality of life was not explicitly flagged as an indicator by professionals in the current research. However, the professionals referred to the importance of children feeling that life goes on. A parallel can be drawn between this theme represented by indicators such as the sense of normality and achievement and those of maintaining hope and finding meaning in life which have been found to characterize the spiritual domain of QoL [e.g., 11, 15]. Importantly, to tap these domains, professionals rely on the collection of non-verbal, relational and contextual cues. This highlights the fact that information sources are varied and should be crosschecked or challenged in order to obtain a picture as complete and reliable as possible of the child's QoL. Furthermore, the level of QoL should be adjusted according to the context, especially when the child is very sick and suffering from severe limitations. The level of QoL should in fact be considered by taking into account the individuality of the child, his or her trajectory of care and the environmental context. The need to take these contextual elements into account makes it indeed difficult to rely on a

simple approach through direct assessment that only focus on the traditional dimensions of QoL [e. g., 21, 34, 35].

The fact that no formal measure is available or used to assess the QoL in PPC leads professionals to adapt to the child's needs according to the priorities they each perceive individually. This can lead to disagreements between different professionals regarding the QoL of a child, as the sharing of relevant information is difficult. This is reflected by the stress put by participants on communication issues. This can be problematic in an interdisciplinary work context where common goals are at the heart of the intervention. These aspects further highlight the importance of communication within teams so that individual perceptions can be shared and disparities identified and resolved [36]. As in assessing pain and emotional distress, the introduction of a formal assessment of QoL - which remains to be developed - could provide a framework for practice that promotes better communication among professionals and with the family [37].

There is a wide variety of information sources that could be used to judge the QoL according to professionals. Yet, having a variety of informants could make it difficult to identify which person should be consulted in order to evaluate the child's QoL (the "best informant") [9, 38, 39], although professionals insist that the child is the best suited to define his/her QoL and that a parent's perspective is essential when communication with the child is impeded. This point of view is consistent with the current assessment procedures in pediatric oncology [e.g., 21, 34, 35]. Importantly, the analysis of the participants' responses emphasizes the importance of their role as informants. This finding

provides a new perspective on how to evaluate the QoL by showing that the diversity of their role, as well as the experience professionals acquire with the families, offer a theoretical and complementary understanding to that of the child and his/her family.

Professionals' recommendations to improve the assessment of QoL. In the context of PPC, care must be coordinated among the various parties involved with the child and his/her family to enable personalized care for the child [4]. In line with this principle, communication within the multidisciplinary team is at the forefront of the improvement areas mentioned [36]. Professionals consider that communication within the health care team is essential in order to reach an agreement regarding the child's QoL, beyond the notes that are on file. This recommendation is consistent with the acknowledged principle that interprofessional collaboration allows for the identification of shared areas across different fields, while narrowing the gap in perceptions among team members. Thus, considering that professionals from diverse professions tend to focus their approach on different areas of QoL, holding interdisciplinary meetings is a way of gaining a more complete and shared understanding of the child's QoL. It also helps ensure the coherence of the content of their conversations when discussing care objectives with families [4, 36].

Another recommendation that professionals brought forth is to better include the child and his/her family in order to adequately reflect their needs. This recommendation is consistent with the philosophy of patient-centered care [40], where communication with the child and his/her family allows professionals to better anticipate their actions and to

consider the child's and family's values and preferences [4, 41]. It is also a way of limiting attribution biases by professionals and ensuring that individualized assessment are carried out, beyond normative criteria alone [18].

Professionals also recommend receiving training that is specific to PPC. Indeed, it is recognized that the appropriate response to the needs of children in PPC and that of their families requires particular knowledge, skills and techniques [42, 43]. The benefits of receiving training about PPC for health care professionals has been demonstrated [44, 45]. For example, the results of a pre-test post-test study conducted with 50 pediatric clinicians who received training about PPC indicated that following training, participants reported increased confidence levels with respect to their knowledge, skills, and emotional support that they provide to children and their families [45]. It is therefore very likely that PPC-specific training allows professionals to better understand the specific reality of children with advanced cancer, thus ensuring a more accurate assessment of their QoL [44, 45].

Finally, professionals of the present study highlighted the value of creating a measurement tool for QoL that would be adapted to children receiving PPC. This would allow the assessment to be more systematized and objective, as it is currently based on the professionals' relational skills and observations. Several advantages have previously been associated with the use of tools for measuring the QoL of children with cancer: it helps with the sharing of information among team members, improves communication with the child and the family, ensures that more needs are met, and simplifies the recording of data

relevant to the child's file [7, 18]. Recent initiatives have developed new strategies [26, 27]. While significant problems of feasibility and recruitment remain, this course of action is nevertheless promising and responds to a current need in the field. Evaluation strategies to be developed should tap the main domains identified in recent research [16].

Strengths and limitations

The limitations of this study mainly concern the sample's composition. 1) This study focused on the signs used by professionals to explore the QoL of children with cancer receiving PPC. The descriptive model therefore does not take into account the points of view of the children and families on QoL. However, it is informative to document professional practices. It should also be noted that the sample comprised professionals working in hematology-oncology, which excludes other clinical contexts that refer to palliative care (e.g., neonatology). 2) The distribution of our sample is also not representative of health care staff in oncology, despite the fact that we tried to include diverse occupations. Indeed, the proportion of physicians is higher than that of nurses. However, it has unlikely led to biases in the presence of certain codes or themes because the data saturation was attained across groups of professions (physicians, nurses, other professionals). 3) As in any qualitative research, self-confirmation bias cannot be ruled out. In order to prevent this problem from occurring, we intentionally used a very open collection procedure as well as methodological safeguards, including the strict upkeep of a journal and the triangulation of the research supervision.

Implications

The present research allows us to discuss the discrepancies between current effective practices and desirable practices as mentioned by professionals. The results of this study therefore suggest the development of a personalized and more systematic evaluation of QoL. We foresee three major implications of the present findings.

First, it is undoubtedly necessary to use several information sources, including child and parents, and signs from different modalities (speech, observation, etc.) to evaluate QoL in the context of PPC, thus approaching a multi-method evaluation that is anchored in the history and current trajectory of the disease.

Second, the assessment must put the child's feelings first and not solely rest on pre-established standards of QoL. An important notion that arises from the present findings is that of the standards or reference levels which the professionals take to compare the actual status of the child. Participants tended to, on the one hand, situate the child's overall QoL according to signs they collect and, on the other hand, to compare this picture to the child's previous and anticipated state with respect to his/her disease. The consequence of this observation is that the approach to assess the QoL in this context should be particularly sensitive to change, for example by focusing on a short temporal perspective such as a day, which is consistent with palliative care practices used with adults [46]. This is coherent with the recommendations of PPC standards, according to which the needs of the child and family evolve through the different stages of the disease. Thus, the assessment of needs should be a continuous, repeated process that occurs on a regular basis according

to the evolution of the child's condition [1, 4]. Feasibility and burden are core criteria for a further assessment strategy in this context.

Third, as much of the criteria used are derived from the clinical observations or judgment of professionals, they can be interpreted differently depending on the professional. This result should guide researchers towards an assessment that is validated by the child's and family's perceptions and by different professionals to avoid attribution bias. A proposed solution is to develop simple assessments that would allow sharing information on the central themes of QoL [16, 47].

CONCLUSION

The results of this qualitative study with 20 professionals in a hematology-oncology department indicate that the assessment of QoL in PPC is currently not formalized and mainly calls for the individual judgment of professionals. Participants reported that the lack of planned or systematized procedures in regard to QoL in their care practices may lead to disagreements on the QoL of the same child in the same situation. To address these issues, professionals recommend interdisciplinary communication, involving the child and his/her family in the assessment process, developing training specific to PPC, and stress the need to create a tool to measure the QoL of children in the context of PPC specifically. Future studies should thus confirm the signs and cues to evaluate the QoL with patients and families, develop a simple and usable tool to assess the QoL. This will allow the sharing of information among professionals, child and family members on the domains relevant to the context of PPC.

LIST OF ABBREVIATIONS

QoL: Quality of Life

PPC: Pediatric palliative care

DECLARATIONS

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Availability of data and materials

The datasets analysed during the current study are formed of full transcripts of interviews. Due to ethical constraints, raw material cannot be shared. Intermediary files, coding an categories are available from the corresponding author on reasonable request.

Authors'contributions

JAB was the primary contributor. She designed the study, collected and analyzed the data and wrote the manuscript

VP co-supervised the project, helped analyze the data and co-wrote the manuscript

LF helped devise the study, interpret the data, and corrected the final manuscript

CL helped devise the study, interpret the data, and corrected the final manuscript

NH helped devise the study and collect the data

MD helped devise the study, collect the data and corrected the final manuscript

SS was the senior author. He secured financial support, co-designed the study, helped collect and interpret the data, and co-wrote the manuscript

Ethics approval and consent to participate

The study received ethical approval from the CHU Sainte-Justine Research Ethics Committee (reference number: 3547) and the University of Sherbrooke Research Ethics Committee (reference number: 2013-1245, 2013-67-LSH/Avoine-Blondin). Written informed consent was collected from the participants during the initial interview.

Consent for publication

Not applicable.

Competing interests

The authors have no conflict of interest or competing interests to declare.

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Table 1 Interview Questions

1. Identifying the professional's perceptions of the child's QoL.	
Questions	According to you, what was it that made this child have a good day? A bad day? A good time? A bad time? Do you remember one of these moments? • [Prompts]: What are the specific indications or elements that allow you to judge whether it is or was a good or bad day for the child? [a] Now, if we think more generally, what do you think defines a good day for a child with advanced cancer in palliative care? And what defines a bad day? • [Prompts]: What are the specific indications or elements that allow you to judge whether it is or was a good or bad day for the child? [a]
2. Identifying the professional's perceptions of the child's QoL and activities or trends involved in defining a good or bad QoL for the child.	
Questions	Could you describe the QoL of the child for whom you provided care to? • [Prompts]: What are the specific indications or elements that allow you to judge whether it is or was a good or bad QoL? [a] If we think more generally about children with cancer in palliative care, what would be the criteria to consider in the evaluation of their QoL? [a]
3. Analysis of the professionals' practices to evaluate the QoL of children with advanced cancer in PC.	
Questions	According to you, are the same criteria to assess QoL used by different professionals? Do you agree on the same child's QoL? [a] What are your recommendations to improve this evaluation? [a]
4. Is there anything else you would like to add concerning the QoL of children with advanced cancer in palliative care? [a]	

[a] The answers of these questions were analysed to meet the objectives of this article.

Table 3. Indicators associated with the dimensions of QoL from the perspective of professionals in hematology-oncology

Dimensions of QoL	Signs	Examples from the verbatim transcripts
Physical comfort	· Level of pain · Amount and intensity of physical symptoms and side effects of treatment (e.g., nausea, vomiting) · Level of satisfaction of physiological needs (e.g., quantity and quality of sleep, ability and level of nutrition, ability to defecate, respiratory condition)	"P: […] when you're nauseous and vomit all day, well I imagine that it did not help him have a good day [...]" P3
Psychological alleviation	· Level of cognitive abilities (e.g., state of consciousness, cognitive impairment and associated symptoms) · State of psychological health and presence of psychological symptoms related to medical condition (e.g., coping ability, level of emotional distress, presence or absence of hallucinations)	"P: Of course we weren't expecting for him to be that present or for him to be able to engage in a big conversation, but that he at least be comfortable, that he not be frightened by, by what he would see, or by his hallucinations…" P1
Fun and the present moment	· Ability to take advantage of the present moment and have fun · Presence of shared moments of fun · Ability and opportunity to engage in one or several activities the child enjoys · Ability and opportunity to get pleasure out of eating	"P: Seeing him laugh, smile, um, getting pleasure out of eating, he was very very happy and he was happy to tell everyone afterwards." P7

Sense of control	· Ability and opportunity to control an activity in whole or in part (e.g., participate in care or lead the game) · Level of physical autonomy (e.g., presence of physical disabilities, deterioration of functional abilities and limitations caused by the losses in activities of daily living) · Ability and opportunity to make decisions · Presence of moments of freedom and independence	"P: if you see a teenager who is bedridden, or who, you know, who is no longer autonomous, I think we all have the same thought. […] we're able to say that, you know, the patient's quality of life has probably deteriorated."P5
Feeling that life goes on	· Ability and opportunity to maintain activities as before the onset of the disease or as same-age peers (e.g., continue to do things like before the disease, play sports, go to the movies) · Ability and opportunity to pursue achievements and accomplish things (e.g., go to school, do crafts) · Ability and opportunity to achieve one or several dreams and wishes (e.g., go on a family trip, see a hockey game)	"P: […] she often talked about school, that she was going to go back to school, and you could see in her face that it was like she was seeing a bit further than just tomorrow (I: Hum hum). She was projecting herself. So, for me, it meant that she felt really good to be able to say: "Wow, I'm going to go back to school, I'm going to see my friends again.". P8
Sense of being valued and recognized	· The child asserts his/her needs and says he/she feels understood · The child seems satisfied with the care provided · The child is included in the decision-making process and informed of the follow-up	"P: […] personally to ask them […] Because I think that the best people to express what they want as a quality of life, I think, are the patients themselves and the families. […] They are best positioned to express their needs." (P2)

	· An interest in the child beyond his/her symptoms is displayed	
Meaningful social relationships	· Ability and opportunity to maintain meaningful relationships de (e.g., presence of the parents, siblings, friends, continuity of care) · The child is surrounded by love and in a context of emotional security (e.g., sharing and signs of affection, the presence of care necessary to ensure safety)	"P: Is the family together? You know, if we have children who live in Chicoutimi and are hospitalized here in end-of-life care, while the rest of the family is in Chicoutimi, um that can't be easy. So, can we reunite the family if that's what they want? Actually, it's to know that family as well as possible to know their wishes. Not to believe that this is what they need, but rather understand what they really want." P20

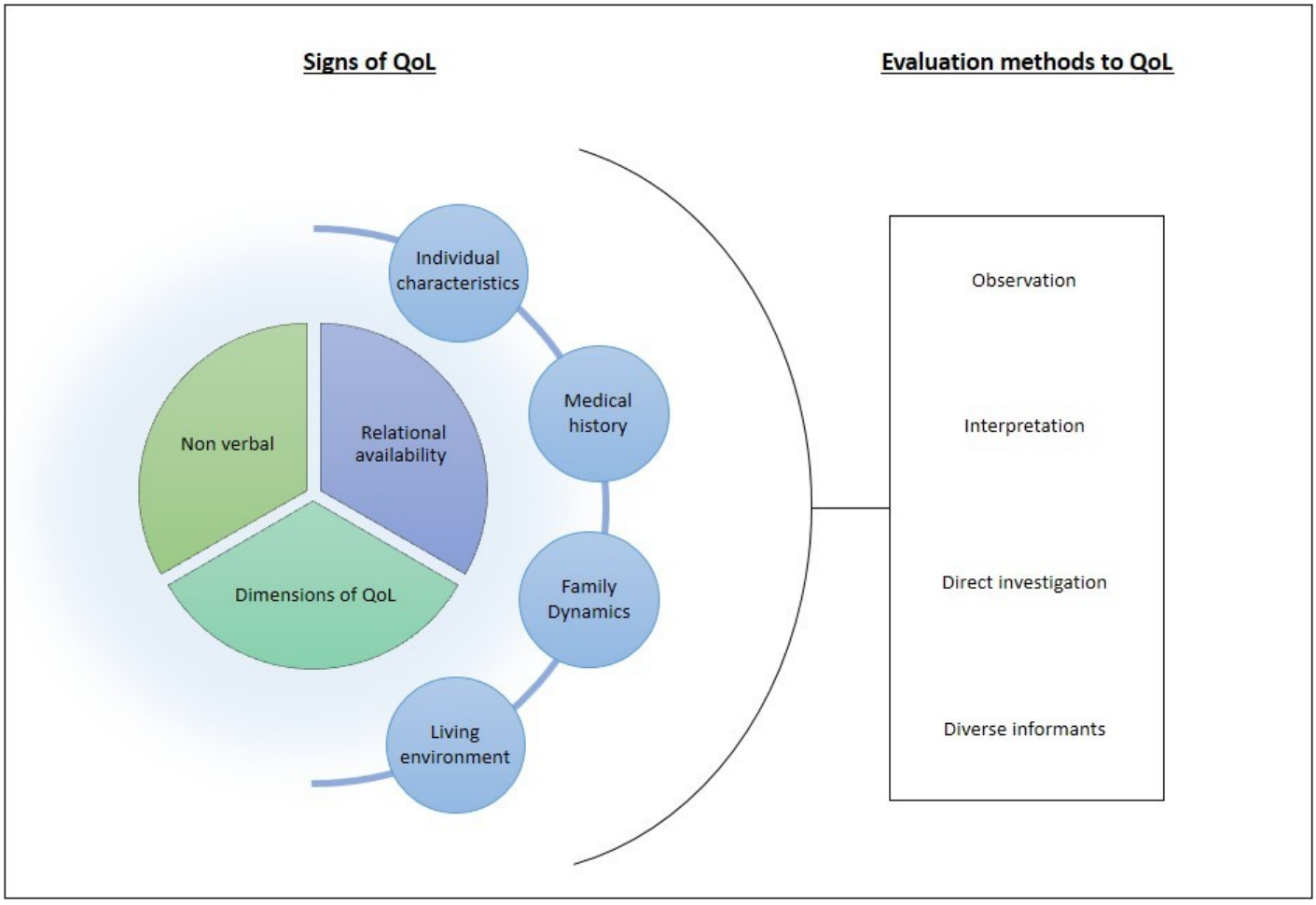

Figure 1 Overview of the signs and ways used by professionals to assess the QoL of children

Conclusion

Le dernier chapitre de cette thèse a pour optique de résumer les principaux résultats de l'étude ici menée pour ensuite préciser leur pertinence sur le plan pratique dans le domaine des SPP en oncologie. Il se divise ainsi en quatre sections. La première section expose une synthèse des résultats des deux articles présentés dans les chapitres 1 et 2. La seconde traite de la pertinence pratique de ces résultats et la troisième présente les forces et limites de la thèse. Le chapitre se termine par une réflexion concernant les possibles pistes de recherches futures.

Synthèse des résultats

La présente étude, axée sur la représentation de soignants ayant accompagné des enfants atteints de cancer avancé et recevant des soins palliatifs, avait deux objectifs principaux : (1) Décrire les dimensions de la QdV dans le contexte des SPP en oncologie ; (2) Décrire les signes indicatifs et les approches utilisés par les soignants pour évaluer la QdV des enfants qu'ils accompagnent et recenser leurs recommandations pour améliorer cette évaluation. Pour répondre à ces deux objectifs de recherche, un devis de recherche qualitatif a été privilégié et une méthode d'analyse thématique de type inductive a été menée.

Article 1

Les résultats associés au premier objectif de la recherche ont permis d'identifier sept dimensions de la QdV: Être suffisamment confortable sur le plan physique; Être apaisé dans sa souffrance psychologique; Être dans la vie, vivre des moments de plaisir au quotidien; Garder un sentiment de contrôle sur sa vie; Avoir le sentiment que la vie continue; Avoir le sentiment d'être estimé et reconnu; Être en relation avec des personnes significatives.

En cohérence avec la documentation existante au sujet de la QdV en oncologie pédiatrique, les dimensions confort physique, apaisement de la souffrance psychologique et relations sociales significatives correspondent aux dimensions de la QdV physique, psychologique et sociale traditionnellement identifiées dans les études s'étant intéressées à la perception des enfants et des parents (p. ex., Eiser, & Morse, 2001; Hinds et al., 2006; Evan, Calonico, Tan, & Zeltzer, 2012).

La perspective des soignants permet en outre de dégager de nouvelles dimensions, davantage centrées sur les potentialités et le vécu positif de l'enfant : Être dans la vie, vivre des moments de plaisir au quotidien ; Garder un sentiment de contrôle sur sa vie ; Avoir le sentiment que la vie continue ; Avoir le sentiment d'être estimé et reconnu. La description générale de la QdV issue de l'analyse thématique du discours des soignants contraste donc avec le portrait habituel de la QdV en oncologie pédiatrique dont les

indicateurs sont principalement liés aux limitations et à la dégradation de l'état de santé général du jeune (p. ex., Knapp., 2012; Tomilinson et al., 2011).

Article 2

Le second article présente un portrait descriptif de la pratique des soignants concernant l'évaluation qu'ils font de la QdV des enfants atteints d'un cancer avancé et suivis en SPP. Globalement, ce portrait révèle que les soignants interrogés n'ont pas accès à des critères préétablis de la QdV en SPP, ni à une procédure systématique à laquelle ils peuvent se fier pour juger de la QdV des enfants qu'ils accompagnent dans ce contexte. Ce constat corrobore ainsi le manque d'outil de mesure de la QdV spécifique au SPP en oncologie, tel que dénoncé par la communauté scientifique (Cataudella et al., 2014 ; Coombes et al., 2016 ; Huang et al., 2010).

Selon le discours de ces soignants, l'évaluation de la QdV est ainsi actuellement laissée à la discrétion de chacun des soignants. Ces derniers se basent de façon partielle et variable sur les dimensions qu'ils perçoivent de la QdV, en l'occurrence les dimensions présentées dans l'article 1, mais également sur des signes indicatifs tels que le non verbal de l'enfant, sa disponibilité relationnelle et son contexte de vie. Pour recueillir ces indices, ils utilisent divers moyens qui ne sont pas planifiés dans leurs pratiques de soins. Ils s'appuient notamment sur leurs observations et leur jugement clinique, lequel inclut des inférences personnelles et empathiques, ainsi que sur des questionnements directs à l'enfant et ses parents. Il est alors reconnu par les soignants qu'une telle variabilité dans la manière

d'évaluer la QdV peut mener à des désaccords entre eux concernant la QdV d'un même enfant et peut être source de problème dans un contexte de travail interdisciplinaire où l'établissement d'objectifs communs est au cœur de l'intervention (St-Cyr Bouchard, 2013 ; Wilson & Seymour, 2017).

De la sorte, afin d'optimiser l'évaluation de la QdV des enfants atteints de cancer en SPP, les soignants évoquent quatre principales recommandations : (1) favoriser la communication entre les membres de l'équipe soignante (2) centrer l'évaluation sur les besoins de l'enfant, la famille et les impliquer dans la démarche d'évaluation (3) recourir à une évaluation formelle pour évaluer la QoL; (4) recourir à des formations spécifiques aux SPP en oncologie. Ces recommandations abondent dans le sens des Normes en matière de SPP énonçant qu'une bonne évaluation devrait être : « globale et faite selon une approche multidisciplinaire par des intervenants qui ont les compétences appropriées et être réalisée en collaboration avec l'enfant et sa famille pour parvenir à une évaluation individualisée qui tient compte des situations particulières » (Gouvernement du Québec, 2006).

Pertinence pratique des résultats

Les résultats de la présente thèse permettent, d'une part, d'élargir et de clarifier le concept de QdV spécifique au contexte des SPP en oncologie selon la perspective de soignants ayant accompagné des enfants dans ce domaine et, d'autre part, de mettre en évidence les écarts entre la pratique actuelle des soignants concernant l'évaluation de la

QdV en SPP et les pratiques souhaitables pour améliorer cette évaluation. Il en découle ainsi des implications tant sur le plan conceptuel que pratique.

Dans un premier temps, il s'agit, à notre connaissance, de la première étude dont la description des dimensions de la QdV est issue d'une démarche inductive basée sur l'expérience de soignants ayant accompagné des enfants dans le domaine des SPP en oncologie. Le modèle descriptif de la QdV ici présenté s'avère donc opportun sur le plan conceptuel puisqu'il apporte un nouveau regard et des informations complémentaires à celles des études précédentes réalisées auprès des enfants et de leurs parents, lesquelles sont principalement basées sur les concepts théoriques antérieurement définis auprès d'une population d'enfants atteints de cancer en cours de traitements curatifs ou survivants (Coombes et al., 2016 ; Hinds et al., 2006; Huang et al., 2010).

De la sorte, davantage centrées sur les potentialités et le vécu positif de l'enfant et tenant compte de la temporalité spécifique au SPP, les dimensions issues de l'expérience des soignants invitent à donner une plus grande opportunité d'expression, durant l'évaluation et l'intervention, à des événements positifs de la vie et au potentiel actuel de l'enfant. Par exemple, en regard des dimensions « Garder un sentiment de contrôle sur sa vie » et « Avoir le sentiment que la vie continue », il s'agirait notamment de favoriser la participation de l'enfant à ses soins pour qu'il puisse en retirer un sentiment de contrôle ou de s'assurer qu'il ait la possibilité d'accomplir des activités et réalisations adaptées à sa condition actuelle malgré les pertes occasionnées par sa condition médicale. Les

présents résultats, ouvrent ainsi la voie à des pistes de réflexion concernant les cibles d'évaluation et d'intervention à privilégier pour améliorer la QdV des enfants atteints de cancer avancé et recevant des SPP. En ce sens, la description détaillée de chacune des dimensions, présentée en chapitre 1, pourrait servir de repère utile à l'élaboration de ces cibles.

Ensuite, les présentes dimensions de la QdV étant issues de l'analyse thématique du discours de soignants de différentes professions, leur catégorisation et appellation offrent une représentation globale de leur expérience. Cette représentation pourrait alors leur servir de référentiel lors de leurs échanges interprofessionnels concernant la QdV des enfants qu'ils accompagnent. L'utilisation d'un vocabulaire commun, exempt de jargon propres à chaque profession, faciliterait ainsi la communication interdisciplinaire en vue d'établir des objectifs de soins communs (Wilson & Seymour, 2017). Nonobstant, l'étendue de ces dimensions étant restreinte au contexte ayant fait l'objet de la présente étude, il s'avérerait pertinent que des recherches futures poursuivent l'exploration de ces dimensions notamment auprès des enfants et parents pour valider leur pertinence et en préciser le construit.

D'autre part, l'exploration de la pratique des soignants à l'égard de l'évaluation de la QdV des enfants atteints d'un cancer avancé en SPP a révélé l'absence d'utilisation d'une mesure systématique et opérationnelle de la QdV. En ce sens, la mise en évidence des signes indicatifs et moyens utilisés par les soignants pour évaluer la QdV et de leurs

recommandations pour améliorer cette évaluation soutient la démarche de développement d'une méthode de mesure formelle de la QdV dans le contexte des SPP en oncologie. À cet effet, en se basant sur les principales conclusions de la présente recherche, l'expérience des soignants propose essentiellement trois caractéristiques à prendre en considération lors de l'élaboration d'un outil de QdV spécifique aux SPP en oncologie.

Premièrement, il serait pertinent que l'évaluation tienne compte d'indicateurs variés de la QdV tout en étant ancrée dans l'histoire et la trajectoire de la maladie de l'enfant. Ainsi, outre la prise en compte de chacune des dimensions de la QdV, le non verbal de l'enfant, sa disponibilité relationnelle et les éléments liés à son contexte de vie devraient être considérés pour avoir un portrait le plus global possible de la QdV de l'enfant. Cette avenue constitue un apport au modèle traditionnel des instruments de mesure actuels puisque la nécessaire prise en compte des éléments de contexte rend difficile un abord simple par des mesures directes et centrée que sur les dimensions de la QdV, telles que généralement utilisées pour évaluer la QdV dans le domaine de l'oncologie pédiatrique (p. ex., Collins et al., 2000; Goodwin et al., 1994; Varni et al., 2001).

Deuxièmement, en portant un regard critique sur la pratique des soignants et en la mettant en lien avec leur représentation de la QdV et recommandations, il semble que l'idéal serait de mettre en commun des mesures auto-rapportées et des mesures effectuées par des tiers, incluant les soignants, afin de fournir des informations complémentaires (Di

Gallo, Felder-Puig, & Topf, 2007). Ces résultats encouragent ainsi d'utiliser plusieurs sources d'information pour évaluer la QdV dans le contexte des SPP.

Troisièmement, la stratégie employée pour évaluer la QdV devrait être particulièrement sensible au changement et administrée de façon fréquente. Les professionnels insistent sur la nécessité d'évaluer la QdV dans une fenêtre temporelle réduite courte comme la journée. Ce point de vue se distingue de la majorité des mesures actuelles en oncologie pédiatrique pour lesquels la période de rappel s'étend souvent jusqu'à 1 mois. L'évaluation répondrait ainsi davantage au fait que la notion de temps chez les enfants repose sur des repères temporels qui se situent dans l'ici et maintenant et qui sont fortement influencés par le contexte présent (Missotten et al., 2007). Elle correspondrait également davantage à la réalité des enfants en SPP pour qui les besoins varient fréquemment et rapidement (Coombes et al., 2016)

Au final, la création d'un outil d'évaluation de la QdV adapté à la population d'enfants en SPP permettrait notamment de systématiser et d'objectiver l'évaluation qui actuellement repose sur les observations et le jugement clinique des soignants. Elle permettrait aussi de faciliter la transmission de l'information entre les membres de l'équipe en s'assurant que tous les aspects des besoins soient couverts. Comme constaté auprès de la population d'enfants atteints de cancer en cours de traitement ou survivant, l'établissement d'une évaluation formelle offrirait un cadre de pratique favorable à la prise de décision avec l'enfant et sa famille en regard à sa QdV.

Enfin, les présents résultats ciblent l'importance de considérer l'expérience des acteurs du milieu qui gravitent autour de l'enfant et de la famille. En ce sens, ils confirment que l'interdisciplinarité a l'avantage de tirer le meilleur profit possible de la complémentarité des expertises variées en vue d'offrir des services complets pour maintenir et améliorer la QdV de l'enfant et sa famille (Gouvernement du Québec, 2006).

Forces et limites

L'originalité de l'étude repose principalement sur le fait que ses résultats sont issus de la perspective de soignants ayant accompagné des enfants atteints de cancer avancé et recevant des SPP et non sur celles des patients ou familles comme l'on fait la plupart des études antérieures (p. ex., Barrera et al., 2005 ; Friedrichsdorf et al., 2015 ; Hechler et al., 2006 ; Tomilinson et al., 2011 ; von Lützau et al., 2012). L'exploration de leur pratique témoigne notamment de l'importance d'inclure le point de vue des divers soignants dans l'évaluation de la QdV afin de faciliter l'établissement d'une représentation globale de la QdV de l'enfant. Le point de vue des soignants est d'ailleurs particulièrement important dans les cas où l'enfant ne peut pas répondre pour lui-même et où une stratégie multi-informant doit être utilisée. Aussi, mieux connaître les représentations des soignants concernant la QDV des enfants qu'ils soignent leur permettra de s'interroger sur leur propre pratique et de fixer des objectifs de soins plus clairs et plus spécifiques aux SPP en regard à la QVD de leurs patients. Ils pourront ainsi faire des choix éclairés quant aux alternatives thérapeutiques et donc évaluer si l'approche de soins est efficace et si elle doit être initiée, maintenue ou cessée (Mulhern et al., 1989; Pellegrino, 2000).

Aussi, les présentes dimensions de la QdV ont été déterminées de façon inductive en tentant de faire abstraction des a priori associés aux dimensions préalablement identifiées dans le domaine de l'oncologie pédiatrique. La description de la QdV est ainsi basée sur l'expérience des soignants plutôt que sur les concepts théoriques antérieurement définis auprès d'une population d'enfants atteints de cancer en cours de traitement ou survivants.

Les limites de cette étude concernent principalement la composition de l'échantillon. Effectivement, bien que l'exploration de l'expérience et de la perspective des soignants concernant la QdV en SPP constitue une force de la présente recherche, elle représente à la fois une limite. Dans les faits, elle n'offre qu'une vision partielle des dimensions de la QdV et du portrait de l'état actuel de l'évaluation de la QdV dans le contexte des SPP en oncologie. Il s'agit ainsi d'une limite notable considérant que nous ne disposons pas du point de vue des enfants et parents qui pourraient confirmer ou infirmer les dimensions de la QdV issues de la représentation des soignants. Ensuite, bien que nous ayons tenté de rencontrer un maximum de soignants de différentes professions, la répartition de l'échantillon ne s'avère pas tout à fait représentative des personnels en oncologie ; la proportion de médecins étant supérieure à celle des infirmières. Finalement, le guide d'entretien peut avoir induit une perspective temporelle réduite par des questions orientées sur la bonne ou mauvaise journée. Toutefois, sur ce point, il est à noter qu'une forte proportion de professionnels décrivent spontanément la QdV selon une perspective temporelle réduite et associée à l'instant présent, ce qui s'avère encore plus restreint que celle proposée par la question d'entrevue axée sur la bonne journée.

Pistes de recherche future

À la lumière des résultats de la présente étude et des limites ci-haut mentionnées, il serait d'abord pertinent que les recherches futures explorent la validité des dimensions de la QdV, telles que représentées par les soignants, auprès des enfants et leurs familles. La mise en commun des différentes perspectives pourrait ainsi donner lieu à une meilleure compréhension du concept de QdV dans le contexte des SPP en oncologie. Une telle clarification du concept permettrait par la suite d'envisager l'élaboration d'une évaluation de la QdV selon la trajectoire de l'enfant avec un cancer avancé, en débouchant sur une échelle de cotation destinée au partage d'information au sein des équipes, mais également avec la famille. La création d'une telle mesure aurait pour avantage principal d'aider les soignants à évaluer les effets de leurs interventions et à prendre des décisions quant aux soins à privilégier afin de s'assurer que l'objectif premier des SPP soit respecté, celui de maintenir et d'améliorer la QdV des enfants.

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Appendice A

Certificat éthique de l'Université de Sherbrooke

UNIVERSITÉ DE SHERBROOKE

Comité d'éthique de la recherche
Lettres et sciences humaines

PAR COURRIER ÉLECTRONIQUE

Le 13 septembre 2013

Madame Josianne Avoine-Blondin
Étudiante
Doctorat en psychologie
Faculté des lettres et sciences humaines

Objet : Reconnaissance de l'approbation du *CÉR du CHU Sainte-Justine* pour le projet : *Étude descriptive de la représentation de la qualité de vie que se font les soignants accompagnant des enfants atteints de cancer suivis en soins palliatifs (CÉR du CHU Sainte-Justine No. De dossier 3547))*
N/Réf. 2013-67/Avoine-Blondin

Madame,

Nous avons reçu les documents relatifs au projet cité en rubrique et approuvé par le Comité d'éthique de la recherche du CHU Sainte-Justine.

Nous avons pris connaissance des documents. En vertu de la *Politique institutionnelle en matière d'éthique de la recherche avec des êtres humains* (2500-028), article 3.3.1 (p9), nous reconnaissons l'évaluation éthique effectuée par le Comité d'éthique de la recherche du CHU Sainte-Justine, de même que l'approbation qui a été donnée par ce dernier en date du 30 juillet 2012 (renouvellement le 26 juin 2013).

Cette approbation étant valable jusqu'au 26 juin 2014, il sera de votre responsabilité de nous faire parvenir soit le renouvellement de l'approbation du Comité d'éthique de la recherche du CHU Sainte-Justine ou votre rapport de fin de projet. Par la même occasion, si des modifications majeures ont eu lieu en cours d'année, nous vous prions de nous faire parvenir la dernière version approuvée des documents concernés.

Le comité vous remercie d'avoir soumis votre demande d'approbation à son attention, vous souhaite le plus grand succès dans la réalisation de cette recherche et vous prie d'accepter ses salutations distinguées.

Dominique Lorrain
Présidente du comité d'éthique de la recherche
Lettres et sciences humaines

c. c. Véronique Parent, directrice de recherche
Serge Sultan, directeur de recherche
Thérèse Audet, vice-doyenne aux études supérieures et à la recherche, Faculté des lettres et sciences humaines

DL/cc

Appendice B

Certificat éthique du CHU Sainte-Justine

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Université de Montréal

Le 06 juillet 2017

Monsieur Serge Sultan
CHU Sainte-Justine

Objet	Renouvellement de l'approbation éthique - CÉR
	2017-1053 Comment les soignants conçoivent la qualité de vie des enfants souffrant d'un cancer et suivis en soins palliatifs pédiatriques? Une étude qualitative auprès de soignants en oncologie visant à dégager les dimensions de la qualité de vie de l'enfant Nago Humbert; Michel Duval; Véronique Parent; Josianne Avoine-Blondin; Magali Lahaye

Monsieur,

L'approbation éthique de votre projet cité en rubrique a été renouvelée par le Comité d'éthique de la recherche du CHU Sainte-Justine en date du 05 juillet 2017 et le document suivant a été approuvé:

- Protocole de recherche non daté

Le formulaire d'information et de consentement n'a pas été réévalué puisque votre rapport annuel indique que le recrutement des participants est terminé.

Veuillez noter que cette approbation est rétrospective et couvre la période allant du 26 mai 2017 au 04 juillet 2017.

Tous les projets de recherche impliquant des sujets humains doivent être réévalués annuellement. La durée de votre approbation sera effective jusqu'au **05 juillet 2018**. Il est de votre responsabilité de soumettre une demande au comité pour que l'approbation éthique soit renouvelée avant la date d'expiration. Il est également de votre responsabilité d'aviser le comité dans les plus brefs délais de toute modification au projet et/ou de tout événement grave et inattendu susceptible d'augmenter le niveau de risque ou d'influer sur le bien-être du participant.

En vous souhaitant une bonne poursuite de votre projet,

Appendice C

Formulaire d'information et de consentement

Formulaire d'information et de consentement

Comment les soignants conçoivent-ils la qualité de vie des enfants souffrant d'un cancer et suivis en soins palliatifs pédiatriques ?

CHU Sainte-Justine
Le centre hospitalier universitaire mère-enfant

Pour l'amour des enfants

Université de Montréal

Chercheur responsable

Serge Sultan, Ph.D. en psychologie, Centre de Recherche du CHU Sainte-Justine

Collaborateurs

Josianne Avoine-Blondin, candidate au doctorat en psychologie, Université de Sherbrooke

Magali Lahaye, Ph.D., Université catholique de Louvain, Belgique

Véronique Parent, Ph.D., Université de Sherbrooke

Michel Duval, M.D., hémato-oncologue, Centre de Recherche du CHU Sainte-Justine

Nago Humbert, Ph.D., Centre de Recherche du CHU Sainte-Justine

Source de financement

Ce projet est financé par le Centre de Recherche du CHU Sainte-Justine.

Invitation à la recherche

Le Centre de Recherche du CHU Sainte-Justine développe des recherches dans le but de mieux comprendre et d'améliorer la qualité de vie des enfants suivis en soins palliatifs pédiatriques. Dans ce contexte, nous nous permettons de solliciter votre participation. Nous vous invitons à lire ce formulaire d'information afin de décider si vous êtes intéressé à prendre part à ce projet de recherche. Il est important de bien comprendre ce formulaire. N'hésitez pas à poser des questions. Prenez le temps nécessaire pour prendre votre décision.

Projet de recherche

De récentes études ont mis en évidence qu'un nombre croissant d'enfants et d'adolescents survivaient à un cancer. Néanmoins, en Amérique du Nord, chez les enfants de moins 15 ans, le cancer reste la deuxième cause la plus fréquente de décès. Au-delà de la prise en charge purement médicale, les chercheurs et les cliniciens accordent de plus en plus d'importance à la qualité de vie globale des enfants atteints d'un cancer. Lorsque les enfants sont en fin de vie, maintenir leur qualité de vie à un niveau optimal est l'objectif principal des soins palliatifs. Aucune étude n'a examiné comment les équipes soignantes conçoivent la qualité de vie des enfants ayant un cancer et suivis en soins palliatifs.

Objectif

L'objectif général de ce projet de recherche est de cerner comment vous, en tant que soignant, vous concevez la qualité de vie des enfants atteints d'un cancer avancé et suivis en soins palliatifs. Nous souhaitons recueillir votre perception sur ce thème.

Participants et procédure

Les participants sont les soignants impliqués dans les soins des enfants atteints d'un cancer suivis au CHU Sainte-Justine.

Vous serez invités à prendre part à un entretien semi-structuré, mené par un chercheur spécialisé en psychologie, qui se tiendra dans un lieu confidentiel. Cet entretien portera sur vos perceptions quant à la façon dont les enfants suivis en soins palliatifs pédiatriques se sentent tant au niveau physique qu'aux niveaux psychologique et social. Cet entretien individuel de 30 minutes à une heure sera enregistré sur un support audio puis retranscrit. Ensuite, il vous sera proposé de compléter un questionnaire d'informations sociodémographiques et professionnelles.

Avantages et risques

Bien que votre participation à cette recherche n'entraîne pas de bénéfice immédiat pour vous, une meilleure connaissance de vos représentations concernant la qualité de vie des enfants semble primordiale pour différentes raisons. Cela pourra notamment vous aider à : (1) contribuer à l'amélioration et au maintien d'une qualité de vie optimale pour les enfants, (2) fournir des critères explicites pour évaluer des traitements ou interventions.

Par ailleurs, les résultats de notre recherche seront utiles pour tout soignant impliqué dans les soins des enfants hospitalisés. En effet, mieux connaître les représentations des soignants concernant la qualité de vie des enfants est un outil important pour s'interroger sur sa propre pratique.

La participation à cette étude n'implique aucun risque ou inconvénient, à l'exception du temps requis pour l'entretien. Si toutefois l'entretien vous amenait à rencontrer des difficultés psychologiques, nous aurons à disposition les coordonnées de professionnels que nous vous transmettrons.

Responsabilité

En signant ce formulaire de consentement, vous ne renoncez à aucun de vos droits prévus par la loi. De plus, vous ne libérez pas les investigateurs et le promoteur de leur responsabilité légale et professionnelle.

Confidentialité

Comme dans tout projet de recherche, à moins d'une autorisation de votre part ou d'une obligation de la loi, vos réponses sont confidentielles. Nous cherchons à mettre en évidence des résultats généraux et non pour un cas particulier. Vos noms et prénoms n'apparaîtront pas sur les

questionnaires. Pour ce faire, chaque participant à la recherche se verra attribuer un code et seul le chercheur principal ou la personne mandatée à cet effet aura la liste des participants et des codes qui auront été attribués. De plus, les renseignements (documents écrits, enregistrements et retranscriptions) seront conservés dans une armoire sous clé située dans un bureau fermé (le du Centre de Recherche du CHU Sainte-Justine et sous la responsabilité de Serge Sultan. Tous ces documents seront détruits 5 ans après la fin du projet.

Néanmoins, afin de vérifier le bon déroulement de la recherche et d'assurer votre protection, il est possible qu'un délégué du comité d'éthique de la recherche du CHU Sainte-Justine consulte les données de recherche.

Par ailleurs, les résultats de cette recherche pourront être publiés ou communiqués dans un congrès scientifique mais aucune information pouvant vous identifier ne sera alors dévoilée.

Liberté de participation et de retrait

Votre participation à ce projet de recherche est libre et volontaire.

Vous êtes également libres de vous retirer de l'étude à n'importe quel moment, et ce, sans qu'aucune justification ne vous soit demandée et sans que cela ait un impact sur vos relations avec l'équipe et les patients.

Personnes ressources

Pour plus d'informations concernant cette recherche, contactez le chercheur responsable de ce projet au CHU Sainte-Justine, Serge Sultan au ou Émélie Rondeau ext.

Pour tout renseignement sur vos droits en tant que participant à ce projet de recherche, vous pouvez contacter le Commissaire local aux plaintes et à la qualité des services du CHU Sainte-Justine au

Nous vous remercions d'avance pour votre collaboration et le temps que vous consacrez à ce projet.

Formulaire de consentement

On m'a expliqué la nature et le déroulement du projet de recherche. J'ai pris connaissance du formulaire de consentement et on m'en a remis un exemplaire. J'ai eu l'occasion de poser des questions auxquelles on a répondu à ma satisfaction. Après réflexion, j'accepte de participer à ce projet de recherche.

_____	_____	_____
(nom du participant)	(date)	(signature)

J'ai expliqué au participant tous les aspects pertinents de la recherche et j'ai répondu aux questions qu'il m'a posées. Je lui ai indiqué que la participation au projet de recherche est libre et volontaire et que la participation peut être cessée en tout temps.

_____	_____	_____
(nom de la personne qui a obtenu le consentement)	(date)	(signature)

Appendice D

Preuve article en cours de révision - How do professionals assess the Quality of Life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement?

Revisions Being Processed for Author Serge Sultan, Ph.D.

Page: 1 of 1 (1 total revisions being processed) Display 10 results per page.

Action	Manuscript Number	Title	Date Submission Began	Status Date	Current Status
Action Links	PCAR-D-17-00206R1	How do professionals assess the Quality of Life of children with advanced cancer receiving palliative care, and what are their recommendations for improvement?	19 Apr 2018	19 Apr 2018	Editorial Assessment

Page: 1 of 1 (1 total revisions being processed) Display 10 results per page.

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